

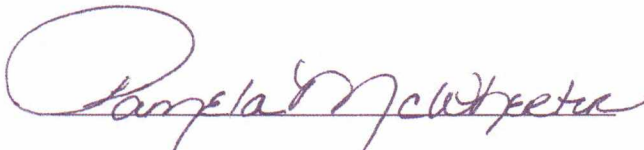
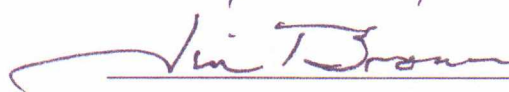
COMMUNICATING STROKE:

A NARRATIVE INQUIRY

By

Mary F. Gelinas

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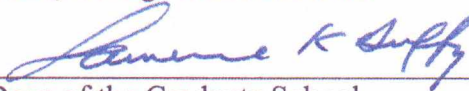


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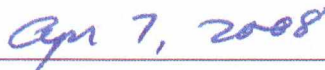
APPROVED:



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Dean of the Graduate School



Date

COMMUNICATING STROKE:

A NARRATIVE INQUIRY

A

THESIS

Presented to the Faculty

of the University of Alaska Fairbanks

in Partial Fulfillment of the Requirements

for the Degree of

MASTER OF ARTS

By

Mary F. Gelinas, B.A.

Fairbanks, Alaska

May 2008

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Abstract

This narrative research in Communication addresses the lived experience of individuals who have suffered stroke. Specifically, I examine how the realities people create and the relationships they enact contribute to their sense of identity after the occurrence of a stroke. Health crises are times of reconstitution of self and relationships (Lorber, 1997). The present research has been conducted from a Human Science perspective, employing the epistemology of Constructionism, the theory of Social Construction of Reality, and Narrative Inquiry and conversational interviewing to produce an understanding of the experience of life after stroke. In this study, stroke survivors are considered active interpreters, managers, and creators of the meaning of their health and illness.

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Chapter 1

Review of Related Literature

1.1 Statement of the Problem and Goals of the Research

My Dad once ran up Mount Greylock, all the way to the top. That's a long run, and a straight shot up. He's told me this story many times, and though my enthusiasm for the details has worn off, it still impresses me. I could picture a younger version of him running up the mountain, just to prove he could. He has always been a hard worker and has never been a man to shy away from a challenge. This may be why he and my mother, a woman of similar temperament, decided to take on the challenge of raising five children and two nephews.

My Dad had a very powerful drive to succeed professionally and to provide for his family. He was always working long hours, hustling around town negotiating the purchase and sale of local properties. Yet in spite of his demanding work hours, his presence permeates my childhood memories. My father was also my middle school basketball coach, my financial advisor, a target for my teen angst, my source for all sports trivia, and my number one fan. I remember watching him play slow-pitch softball at the park on hot summer nights, and going to amusement parks when I was too cool to associate with a grown man who was *that* enthusiastic about roller coasters.

He was only in his early fifties when he had his stroke, but by then I had grown up, gone to college, and moved to Boston, a couple hours away from my childhood home. When I got the call, my initial reaction was disbelief. The stroke, caused by a complete occlusion of his right carotid artery, had affected the left side of his body,

leaving that entire side numb and causing the left side of his face to droop. By the time I made it to the Intensive Care Unit, he was already hooked up to a variety of machines, measuring I knew not what. My mom, features rigid with tension, was holding his right hand as he slept. He looked sick, frail, and so very vulnerable. Though not as spry as when he was younger, my father at fifty was still an active and energetic man. A typical day may have included an early morning trip to the gym, followed by a series of meetings with clients, then maybe a round of golf, or dinner and a movie with my mom if it was Friday night. When I saw him lying there I feared for him the loss of his lifestyle; all his comfortable routines made uncomfortable, challenging, and frustrating in the wake of his stroke.

Over the next few days, thanks to the quick response of the Emergency Medical Technicians and the expertise of his health care providers, his condition stabilized. During the next several months, both in in-patient rehabilitation and following discharge, he regained much control over the left side of his body. He re-learned how to walk, initially with a walker, then a cane, and later without the cane. He also regained feeling in his face, which helped him control the drooping, and the slurring of his speech. Encouraged by this progress, and concerned about being away from his business for too long, he returned to his career as the broker/owner of a Re/Max franchise shortly after completing therapy.

Unfortunately, while he has recovered a substantial amount of his physical abilities, he has additional complications which have impeded a return to his pre-stroke lifestyle. He gets tired much more easily now than he did before because stroke affects

the entire nervous system, even though it may paralyze only certain sections of it, depending on the location of the clot. He also suffers from chronic pain, which he describes as a constant and acute pins and needles sensation, intensified when in contact with even the lightest pressure. In the months following his stroke, this pain only intensified. A battery of tests and a variety of therapies, including pain medication, a spinal implant, routine acupuncture treatments, and even a series of visits to a shaman, afforded him little relief from his pain. Further, he experienced some radical departures from his pre-stroke behavior patterns that he could neither understand nor justify. For example, similar to a sneeze, which is considered an involuntary action over which one has no control, my father, as do most stroke patients, experiences involuntary and unprovoked crying.

Very few emotionally healthy people can take in stride the overwhelming shock to the central nervous system that a stroke brings with it, and my dad had great difficulty adapting at first. These complications had a severe impact on his lifestyle: working, traveling, driving, dining out. The activities he had carried out mindlessly every day of his life became challenging and potentially frustrating endeavors, and while this was difficult for everyone in my family, it affected my mom the most deeply. For committed partners, stroke quickly changes from *his* or *her* stroke to *our* stroke. My mom, totally unprepared for such a disaster, was overwhelmed by how dramatically their lives had changed overnight. Appointments had to be changed or canceled, social activities abandoned, time control completely rearranged. I remember how tense she seemed for months afterwards, trying to juggle her workload as a teacher and caring for him.

My dad started going out less and spending more and more time in his darkened bedroom, alone in his recliner, watching television. A stroke is one of the few human ills where learned professionals tell you there is nothing more that medical science can do for you. The finality of the neurologist's prognosis should not be underestimated. When he was told the pain may never go away, and there was nothing more that could be done for him, I think he felt despair and hopelessness. Whereas some in his situation strike out at God, or the world in general, or try to deny the change, others like my dad retreat from the company of others and self-impose a fate of isolation and loneliness.

Time has helped him come to terms with his stroke, and while my dad still periodically retreats from the world, he has used the insights he has gained in his experience living with stroke in shaping a post-stroke identity that allows him to reintegrate into his community. Stroke left my father vulnerable and dependent on others, which has imbued him with a greater sense of humility and appreciation. He is more patient with others, because they are more patient with him. He has more empathy for the suffering of others, and is far quicker to recognize and assist another disabled person than before. He has also become far more religious in the wake of his stroke experience. A church-going Roman Catholic his whole life, he has become much more strongly committed to his faith. He sees his suffering as a part of God's plan, not necessarily for him to understand, but to endure with strength and courage, and with faith in God's goodness.

As I watched my dad struggle to come to terms with living with stroke, I wondered if there was any literature available that examined what life after stroke was

like on a day to day basis, or that discussed the experiences of stroke survivors from the perspective of the stroke survivors themselves. I perceived that the most pertinent opinions and the best guides for teaching others how to cope with stroke are those who have lived through the experience themselves. I anticipated that other stroke survivors would also have undergone a perspective shift in constructing new post-stroke identities. However, even though stroke is the third leading cause of death in America, and the number one cause of adult disability, there exists a scarcity of information concerning the individual, relational, and societal impact of stroke.

As a Communication scholar undertaking my Masters research at the University of Alaska Fairbanks, I believe that if one wants to understand how people understand an experience such as stroke, one must examine the communicative practices that give rise to the meanings they construct. New insight and understanding can be achieved by studying how people frame their life experiences in everyday conversation. Anderson and Marlett (2004) contend that knowledge of “what recovery from stroke means, how we communicate about stroke disability and life after stroke are imprecise” (p. 441). They suggest that “communication is perhaps the most essential ingredient in effective health care and could be one of the most powerful tools in stroke recovery; yet informal interpersonal communication has received very little attention” (p. 55). Effective communication has been shown to increase satisfaction for both the patient and the provider, to reduce anxiety, improve understandings of risks and benefits, contribute to patients’ sense of control, help make definitive decisions about treatment courses, increase satisfaction with those decisions, and improve compliance with treatment. It is

somewhat disconcerting that despite this evidence, there has been little research on communication in the aftermath of stroke.

In this narrative research in Communication, I will address the lived experience of individuals who have suffered stroke. I consider stroke survivors to be active interpreters, managers, and creators of the meaning of their health and illness, and am interested in how the realities they create and the relationships they enact contribute to their sense of identity after the occurrence of a stroke. This research seeks to uncover the ways in which individuals participate in the creation of their perceived realities. As the daughter of a stroke survivor I am invested in coming to an understanding of the experience of living with stroke. I perceive that a better understanding of how the stroke experience is interpreted by stroke survivors themselves can lead to strategies that more effectively aid in the construction of a positive and empowered post-stroke identity. In this chapter I will review literature that is currently available addressing the phenomenon of stroke. I will discuss stroke rehabilitation as it is conceived at present, the social construction of illness and identity, and the role of social support in the negotiation of identity after stroke.

1.2 Research on Stroke Rehabilitation

Before discussing the potential consequences of stroke, one needs a basic understanding of what the physiological event entails. Put simply, a stroke occurs whenever blood flow is interrupted to an area of the brain. This interruption may be caused by a blood clot blocking an artery or through the breakage of a blood vessel. When either of these events happen, brain cells begin to die and brain damage occurs.

When brain cells die during a stroke, the abilities controlled by that area of the brain, such as speech, movement, or memory are lost. Implications for the individual who has suffered a stroke are contingent upon where the stroke occurred in the brain and how much of the brain was damaged. Someone who has a small stroke may experience only minor problems such as weakness of an arm or leg, whereas people who have larger strokes may lose their ability to speak or become paralyzed on one side of their body. While some people are able to achieve a complete physical recovery, more than two thirds of survivors are left with some type of disability.

While Anderson and Marlett (2004) have highlighted the need for more in-depth analysis of post-stroke communication, much of the literature currently available concerning the consequences of stroke is restricted to examinations of the physical and functional deficits incurred, and the ways in which stroke sufferers can be rehabilitated most successfully. Whereas this research has been undeniably critical in improving the health outcomes of stroke sufferers, it is distressingly limited when one considers the scope of problems that can arise when one suffers a stroke. Much of this literature focuses on the acute stage, when survivors are usually still in the hospital as it is during this stage from a medical perspective that most of the recovery work is thought to occur. From the perspective of stroke survivors themselves, however, the bulk of the work occurs once they return home, because the return home is when “the work of renegotiating, relearning and reorganizing life begins” (Pound, Gompertz, & Ebrahim, 1999, p. 126). In spite of these findings, it appears that “healthcare professionals and service providers continue to ignore the broad, long-term outcomes in terms of a

continuum of impairment, disability and handicap, and what that means to the individual” (White & Johnstone, 2000, p. 140).

White and Johnstone (2000) suggest that after rehabilitation, the survivor is expected to take control of their situation and strive to manage their life in light of their changed circumstances. However, following rehabilitation, the impact of sudden or unexpected disability, handicap, or limitation “draws together many influences which may act upon the individual and their family, affecting in the long-term, their ability to successfully interact physically and socially within the community” (p. 140). Whereas there is a great deal of discussion regarding the extent to which care givers cope with looking after friends or relatives with stroke, there is relatively little on the coping strategies of stroke survivors themselves (Pound et al., 1999). Banks and Pearson (2004) contend that “much of the literature conceptualized people with stroke as passive in response to their situation rather than active and imaginative” (p. 414).

Traditional models of rehabilitation are embedded in medical principles of cure. Their limitations have been discussed at length, and the need to examine the social aspects of recovery has been acknowledged by many health care professionals. Burton (2000) suggests that these examinations take into account how patients themselves experience their recovery from stroke, rather than professional perceptions of their recovery alone. He asserts that “there is generally a dearth of literature that focuses specifically on the individual’s experience of the disease itself” (p. 302). Medical professionals often gauge progress using criteria related to functioning, mostly from a physical perspective, whereas stroke survivors themselves will likely frame their progress

in terms of the activities that brought meaning to their life prior to their stroke. White and Johnstone (2000) assert that, as with all chronic illnesses, “stroke represents an assault upon many areas of everyday life, encompassing home, work, leisure and social relationships including relationships with self and others. It may shatter personal images, family life, and future ambitions” (p. 141). A study by Folden (1994) is sensitive to the lived experience of stroke survivors suggesting that many stroke survivors have the ability to accept that they will never be able to return to their pre-stroke life, and are likely to set personal goals that help them undertake some of their pre-stroke activities.

1.3 Social Construction of Illness: What does recovery mean?

Many health communication researchers have come to be critical of how disability and recovery are framed by medical professionals. Whereas biomedical and rehabilitative models of stroke recovery focus on the viability and process of neuronal and physical recovery in terms of performance in activities of living, these markers of recovery are usually predetermined by health-care professionals with little input from stroke survivors themselves (Burton, 2000). According to McPherson, Brander, Taylor, and McNaughton (2004) “criticisms exist about the lack of consultation about what constitutes meaningful health outcomes” (p. 988). These authors suggest that the “lived experience of disability” and “insider perspectives” are often outside the purview of clinicians. In a similar vein, Anderson and Marlett (2004) highlight the discrepancy between the outcomes considered desirable within the medical community, and the outcomes considered valuable by the stroke survivors themselves. They posit that whereas professionals communicate about treatment of the patient’s disease, bodily

impairment, and problems of reduced functioning stroke survivors portray themselves as people with a life in society that they wish to regain.

The traditional medical model, which still holds much of the Western world in its iron grip, approaches illness in terms of the symptoms experienced by the patient. Overly simplistic in its notions of health and illness, proponents of the medical model correlate health with an absence of symptoms, and illness with their presence. This model presumes that disease is a departure from normal biological functioning, that diseases have identifiable causes that can be located in the body of the ill person, that diseases have the same symptoms and results in any social situation, and that medicine is socially neutral (Lorber, 1997). Newsome and Schultz (1998) contend that in “the traditional medical model, health and well-being are often defined by professionals as what was pre-stroke. Any disability is defined as a deficit; pre-stroke life is superior; post-stroke life is seen as devastating and substandard” (p. 177). For permanently disabled stroke survivors this approach leaves little hope for the future. It also fails to align with research findings by Anderson and Marlett (2004), and others, which indicates that many people who are successful at achieving a full recovery on commonly used scales designed to measure disability or dependence in activities of daily living (Barthel Index and the Modified Rankin Scale), still report “poor quality of life, suffer from significant depression, avoid social activities, and have a negative sense of self” (p. 442).

An alternative to the medical model exists in the form of Lorber’s (1997) notion of the social construction of illness. Lorber suggests that what people actually experience as illness is any disturbance in their social lives which prevents them from pursuing their

usual, everyday activities, which may or may not be the result of actual physiological dysfunction. She asserts that although illness is located in the body, as a social experience it exceeds physiology and involves all aspects of social life, such as “interlocking social roles, power and conflict, social statuses, networks of family and friends, bureaucracies and organizations, social control, ideas of moral worth, aspects of work and occupations, definitions of reality, and the production of knowledge” (p. 4). Whereas feeling ill or healthy is a personal experience, our understandings of what health and illness mean are drawn from the amassed knowledge of the relevant culture (Miles, 1991). Lorber (1997) contends that:

In every society, the symptoms, pains, and weaknesses called illness are shaped by cultural and moral values, experienced through interaction with members of one's immediate social circle and visits to health care professionals, and influenced by beliefs about health and illness. (p.1)

White and Johnstone (2000) assert that “people do not become less human, less interesting or less deserving because they have un-resolvable disabling conditions” (p. 142). Rather they continue to be active interpreters of their experience, learning to adjust, vary, revise, and amend so they may live their lives as best they can manage. In other words, they “seek a state of health that represents their best effort within the specific challenges of their condition” (p. 142).

To be human as we understand it is to be fundamentally, irrevocably social in nature. As a social constructionist, I perceive that all meaning is constructed in communication. Through the communicative interactions we engage in, we develop

increasingly sophisticated understandings of behaviors and beliefs that are socially acceptable or unacceptable. As we communicate with those around us, we co-construct meanings and interpretations for the events we experience. Over time we begin to overlap in our meanings and interpretations with those with whom we repeatedly interact. All meaning is created, recreated, and re-imagined in these communicative interactions. This process of social construction extends to every facet of our personhood; our understandings of who we are, and how we should interpret life events is developed in communication with others. Understanding the fundamental role communication plays in the meaning-making process leads us away from approaches to understanding or conceptualizing illness in terms of physiological symptoms alone.

Insight into how patients experience illness is vital to the development of appropriate strategies to aid recovery. Whereas one's interpretation of their health is critical to their sense of being, their notion of personal identity, and their understanding of reality, people are rarely conscious of or able to articulate their meanings for health (Shulka, 2001). Following the biomedical model, most studies describe stroke recovery using an incremental, linear paradigm. A shortcoming of this approach articulated by Burton (2000) is that it "supposes a normal path of recovery" which "focuses attention on the physical domains of recovery within a time-frame largely dictated by the boundaries of professional service" (p. 307). At present, most patients and their families initially look to rehabilitation as the main therapy that will restore their independence and 'normality' after stroke (White & Johnstone, 2000).

Following the acute stage immediately after the stroke, the patient's growing awareness of their physical limitations may be accompanied by an expectation of a fairly rapid and complete recovery. White and Johnstone (2000) contend that "patient's views of recovery are based on their past experiences of physical illness or injury" (p.141). Those who have led relatively healthy lives prior to suffering stroke may thus have a quite limited understanding of the potential impacts of their stroke on their personal, relational, and social experiences. Understandably, such a negative life event is often followed by feelings of anger, grief, depression, and anxiety. Within the medical model, these reactions are habitually categorized as 'mood disorders' and referred to mental health practitioners (White & Johnstone, 2000).

Unlike people whose conditions have cures and who therefore can be restored to their former selves, people with chronic conditions such as stroke are required to modify their roles and establish new patterns of behavior. However, in order to do so successfully, stroke survivors must transform fundamental assumptions they have developed over their life's course about who they are, and where and how they fit into their social worlds. The paths of recovery from stroke that are reported by survivors are extremely varied in the type and severity of physiological, emotional, and social problems encountered, as well as in and the personal implications these problems pose (Burton, 2000). The process of re-imagining life after a stroke has been found to involve a multiplicity of "physical, social, and emotional issues that varied as an individual adapted to their individual circumstances and contemplated the implications of their stroke on their future lives" (p. 304). This perspective necessitates that the central

disciplinary approach be Communication, because social construction asserts that human realities are created, maintained, and transformed in communication (Deetz, 1982).

1.4 Social Construction of Identity

Persons create their identities in their interactions and negotiations with those around them. The self, as humans understand it, is a distinctly interactive, interpersonal concept, and communication with others is an essential medium for self-development (Anderson & Marlett, 2004). Who we understand ourselves to be is socially constructed (Gergen, 1994; Gergen 2001; Harre, 1995). Richey and Brown (2006) assert that if human reality is continuously formed and transformed through communication, then “self is a product of social interaction, contextually constituted within an intersubjective framework of communication” (p. 4). One’s sense of self is created through the interpretation of life experiences, cultural influences, and the relationships in which one is engaged. Identity is at the core of how one understands health and acts on those understandings, and “because identity is itself the product of communicative interactions, communication must be at the very core of what it means to be healthy” (Lambert et al., 1997, p. 36).

Kaufman and Becker (1991) contend that stroke incurs a profound assault on what they identify as the “natural right sense of self” and the “taken for granted body.” When one suffers a stroke, one’s sense of continuity with one’s past is undermined and one’s future becomes unpredictable (Ellis-Hill & Horn, 2000). Since stroke impacts many areas of life at the same time, it affects “the assumptive world and life-space of the stroke survivor” (Anderson & Marlett, 2004, p. 441). Recovery from stroke thus involves

adaptation and redefinition in all aspects of an individual's life. Tasks and activities that had been taken for granted before suddenly present new challenges, which requires "appraisal, considerable effort and learning, and re-appraisal" (Burton, 2000, p. 304). Kelly and Millward (2004) suggest three ways in which illness and physical impairment in the chronically ill can challenge previously held conceptions of self. First, they assert that chronic illness can impact the self image rooted in one's physicality. Secondly, identity is influenced by the conscious regime of maintenance, or in other words, by the daily medical routine that must be followed by most chronically ill people. Lastly, chronic illness may engender a self-consciousness stemming from a loss of spontaneity. These aspects of chronic illness often leave the sufferer wondering whether they are still the same person, given that they can no longer do what they used to do in the way they used to do it.

Social support has been associated with quicker and more comprehensive functional recovery after stroke (Pound et al., 1999), and stroke survivors have reported that how other people reacted to them was "important in the preservation of self-esteem and in the formation of social identity" (Murray & Harrison, 2004, p. 812). Survivors perceived ambiguous symptoms such as an awkward gait or slurred speech as particularly problematic because they were often misinterpreted by those unaware that the source was a stroke. Murray and Harrison (2004) describe an experience relayed to them by a stroke survivor who was not allowed on a bus because the bus driver interpreted his unnatural gait and slurred speech as a display of public drunkenness. Stroke survivors have also reported perceiving the necessity of a walking aid as a barrier to satisfying social

interactions, both because it engendered a lack of self-confidence in the user, and because it led to feelings that others assumed they were using the aid as a means of getting attention.

In addition the social environment in which the survivor lives after a stroke, the communicative interactions that they engage in, and the response of others to those choices, can either promote or hinder their belief in their ability to solve problems and control their situation. Teasell, Doherty, Speechley, Foley and Bhogal (2002) assert that, “the transition of the stroke experience calls for the need to re-establish functional independence while incorporating residual deficits into a new personal identity” (p. 56). Many disabled individuals do not accept a disabled identity because they do not consider their impairment an important aspect of their personal identity. In the end, the decisions that make a patient a survivor, or a victim, a fighter or a quitter, are informed by their interpretation of their interactions with others.

For some stroke survivors, the loss of cognitive and physical abilities were perceived as “more than disruptions in their personal biographies but as a profound loss of self, or part of self” (Murray & Harrison, 2004, p. 810). Pre-stroke activities and skills lost following a stroke “were so interwoven with participants’ sense of identity that many years later they still conveyed their difficulty in coming to terms with the loss” (p. 811). Ellis-Hill and Horn (2000) posit that:

when individuals cannot create a clear sense of future self, they experience anxiety and become unsure how to act....individuals who have had a stroke may

settle for a restricted future self with limited physical and social activity, because this is what they have been told to expect of a life with disability. (p. 283)

Survivor perceptions of health, illness, sickness, and disease are connected to their sense of what is normal and what is not, which roles they should enact, and what the changes they experience mean.

Stroke has the potential to radically alter an individual's assumptive world view. People rarely conceive that such a devastating medical event could happen to them, so when it occurs, which is often swiftly and without warning, many have difficulty incorporating new limitations and deficits into their sense of personal identity. Our identities emerge in interaction with others, and as such, the communicative practices by which survivors construct and perform identity after stroke should be researched and discussed.

1.5 The Role of Social Support

Researchers suggest that another critical element in stroke survivors successful identity renegotiation is the extent to which they are able to successfully re-integrate into society. Lorber (1997) contends that "illness takes place within a web of interaction that ties together the person concerned, family, friends, co-workers, health care professionals, medical bureaucracies, the physical setting, the technology, government policies and politics, economics, values, knowledge, and beliefs" (p. 95). Social support, or "the experience or information that one is loved and cared for, valued and esteemed, and able to count on others should the need arise" (Pound et al., 1999, p. 126) plays a critical role in the recovery process. Egbert, Koch, Coeling, and Ayers (2006) assert that

“communication processes are the medium through which support is provided to individuals as they cope with everyday stresses and health crisis” (p. 268). Albrecht and Goldsmith (1994) further validate the importance of supportive communication for recovery, contending that “supportive communication plays a complicated, direct, and mediating role in the course and experience of health and illness” (p. 277).

Community re-integration, defined by Egbert et al.(2006) as "re-establishing, to the degree possible, previously existing roles and relationships, creating substitute new ones, and assisting people in making these changes" (p. 46) is often pivotal to stroke survivors perceptions of successful recovery. The social context of recovery is important because most stroke survivors focus on recovery that will “enable participation in the social world through adaptation and the development of coping skills, rather than improvement in discrete physical function alone” (Burton, 2000, p. 307). After a stroke, social roles are challenged and subject to enforced revision, with “once comforting and welcoming environments appearing as potentially hostile territory” (Burton, 2000, p. 304).

Egbert et al. (2006) identify seven challenges to successful post-stroke community integration: physical, cognitive-perceptual, emotional, relational, employment, financial, and activities of daily living. The most commonly described physical impairments reported by stroke survivors include weakness, fatigue, pain and loss of mobility. Cognitive-perceptual challenges reported included difficulty relating elements in context, following a logical sequence of steps, or solving conceptual problems that people encounter on a daily basis. Emotional challenges were identified as

greater emotionality, a desire for seclusion, depression, frustration, anger, and anxiety. Stroke survivors also reported new challenges dealing with their daily activities, such as bathing, dressing, preparing meals, cleaning, and yard work. The most frequent relational challenge mentioned had to do with being an imposition on family and friends, as well as changes to the roles they previously had. For example, being able to drive was reported as being particularly important to male stroke survivors. Employment challenges include stroke sufferers being fired, laid off, or changing jobs due to reduced physical capacity. Those who were fired described feeling angry and struggling to restore their sense of self. Finances were perceived to be a major concern, ranging from meeting basic needs, to medical expenses, getting insurance to cover costs, and dealing with potential job loss. The success of post-stroke recovery clearly depends on the extent to which stroke survivors are successful at tapping into the resources of those within their social network to aid in navigating these many challenges.

Research also indicates that married stroke survivors who have large and supportive social networks have an increased chance of successfully returning to an independent living situation (Egbert et al., 2006). Although current research rarely addresses the impact of stroke on the identities of those closest to the survivor, they must also undergo a similar process of renegotiation and re-identification. Anderson and Marlett (2004) posit that these changes in others are often overlooked because the person with the stroke is the identified patient. However, shifting roles from partner to care giver, taking on tasks formerly done by the partner prior to their stroke, and dealing with any cognitive and behavioral changes in their partner may be as intimidating an identity

metamorphosis as that faced by the stroke survivor themselves. How successfully partners are at this renegotiation process has implications for stroke survivor success.

It is important that researchers examine more thoroughly the impacts of stroke on the relational dynamics of the family unit, particularly those of married couples or life partners. Since stroke requires a redefinition or reconstruction of self on the part of the survivor, the social construction of identity implies that those closest to the survivor must also undergo identity reconstruction in order to accommodate those changes and aid survivor reintegration. Banks and Pearson (2004) observe that “when a family member experiences illness, other family members have to adapt to a change in roles, structures and ways of relating” (p. 426). They reinforce this notion of interconnectedness when they draw attention to the difficulty of sorting out the caring situation “from the relationship in which it is experienced and the need to recognize that the individual needs of carers and cared for are often inextricably linked, based on the shared history and emotions pertaining to their relationship” (p. 415).

Many obstacles may hinder such familial reintegration. Most studies that have examined relational problems post-stroke find that greater problems are reported by relatives than by stroke patients themselves (Visser-Keizer, Jong, Deelman, Berg, & Gerritsen, 2002). Family members, particularly spouses who also have taken on the role of care giver, experience additional strain and relational difficulties. Kurz and Cavanaugh (2001) found that a source of relational stress was the number of novel and critical roles the well spouse had to take on. The participants in their study reported the difficulty of being attentive to their spouse's physical condition and needs, while still fulfilling their

work responsibilities. Additionally, individuals in care giver marriages have described a diminished ability to attend to the quality of their marriage, which may result in loneliness, depression, and reduced physical intimacy for both (Carter & Carter, 1994). Research has shown that “individuals who provided care to a spouse with a disability were six times more likely than non-caregivers to experience depression or anxiety (Cannuscio, et al. 2002). Stroke survivors may also experience difficulty accepting care from their partners. A study on care giving from the recipient's point of view revealed that spouses with disabilities had negative reactions such as low self-esteem and depression related to having their spouse care for them (Newsome & Schutz, 1998).

The goal of post-stroke communication should be to support survivors and their families in creating positive post-stroke identities. Since medical limitations preclude the curing of all conditions, medical professionals should direct more resources towards the positive reframing of narratives concerning life with residual disabilities (Anderson & Marlett, 2004). Communication is the means by which social resources for coping and recovery can become personal resources and vice versa. Gordan and Perrone (2004) recommend that stroke survivors and their partners discuss concerns with each other and recognize that they may have different understandings about how the illness impacts their life. Rolland (1994) posits that "sensitive, open, direct communication about a range of issues is essential to living well with chronic disorders" and that "identifying and normalizing difficult feelings, establishing clear illness boundaries, and re-balancing relationship skews all require effective communication" (p. 329). However, Speziale (1997) cautions against couples relying solely on one another for support, as the practice

places an "impossible burden on the relationship" (p. 23) and can cause a distancing from potentially beneficial resources. Gordan and Perrone (2004) suggest that support groups for both stroke survivors and their care givers can be beneficial for "reducing social isolation, being able to share feelings with others in similar situations, and normalizing care giver experiences" (p. 29).

At present, a lack of research exists concerning how stroke survivors themselves interpret their stroke experience. While studies approaching stroke from the traditional medical model conceptualize health in terms of physiological symptoms, individuals who have actually suffered a stroke construct their own meanings for what it means to be healthy or ill. Knowing more about how survivors ascribe meaning to their stroke, and the implications that has for how they perceive themselves, will improve our ability to provide health care that addresses their concerns most effectively. As the daughter of a stroke survivor, I have found that research that situates health in the experience of everyday living is both lacking and needed.

Chapter 2

Research Methodologies

This study seeks an understanding of how individuals who have survived a stroke make sense of their circumstances. I sought this understanding by eliciting the lived experiences of my co-researchers as to how they interpret life after stroke. My intention was to better describe the particular lived experiences of my co-researchers, and to understand stroke in terms of themes that emerged from their shared experiences, in conjunction with my own. I anticipated that my co-researchers would have constructed meanings for stroke survivorship that differed from one another.

2.1 Research Contexture

In order to better understand how this study differs from those conducted by previous researchers on similar topics, it is important that I illuminate my perspective on scientific research. I begin by inventorying my stance at each level of the research contexture, and unpacking what is meant by each of these terms, as they relate to the doing of human science research. Crotty (1998) addresses the importance of a systematic structure for those interested in undertaking the research process. He proposes that researchers make decisions with regards to their research within a contexture, which spans from ontology and epistemology, to theoretical perspective, to methodologies, to methods. This study employed the ontology of Realism, the epistemology of Constructionism, the theoretical perspective of the Social Construction of Reality, the research methodology of Narrative Inquiry, and conversational interviews and thematic analysis as the specific methods by which data/capta were gathered and analyzed.

2.1.1 Ontology and Epistemology

It is critical that the conscientious researcher clarify at the outset of her research what she perceives the nature of reality to be, and what kind of knowledge she believes is possible. In doing so, I am clarifying how my positioning at every level of the contexture informed how I undertook my research, interpreted my findings, and presented my results to readers. Ontology and epistemology need to be explained in conjunction with one another, because one's perception of ontology, or "what is," (Crotty, 1998, p. 10) is closely linked with one's epistemological stance, which, as Crotty describes "is a way of understanding and explaining how we know what we know" (p. 3). With respect to scientific research, epistemology provides a philosophical basis for determining what types of knowledge are possible, and how we can ascertain that such knowledge is sufficient and authentic. Ontologically, this research is rooted in Realism, which posits that matter and energy exist outside the subjective human mind. Epistemologically, this research is foundationally Constructionist, and as such, it rejects the idea that meaning exists in objects and can be discovered. Constructionism as an epistemology suggests that meaning is created through lived human experience and interaction. Crotty proposes that meaning arises "in and out of our engagement with the realities in our world" (p. 8).

Stemming from this epistemological understanding, human science researchers purport that all human meaning is constructed in interaction with the world. Since every individual constructs their own meanings for their experiences, it is possible that different people will create different meanings with regard to the same event. Constructionists assert that objective truth claims are impossible because the human world is inherently

interpretive. Constructionism aligns nicely with a Realist ontology in that it does not suggest that there is not a world beyond that which is created by the human mind; this world simply does not become meaningful to humans until they confer meaning, which they do according to their experiences.

2.1.2 Theoretical Perspective

In the research contexture, the theoretical perspective is “the philosophical stance that lies behind our chosen methodology” (Crotty, 1998, p.7). The theoretical perspective anchoring the methodology for this study is the Social Construction of Reality. Social Constructionism holds that meanings are created in the process of interaction between individuals; people co-construct their understandings and interpretations through their interpersonal communication. Constructionists assert that as humans we are situated in a variety of cultural contexts which inform the ways in which we interpret the world. For example, one’s nationality, religion, group affiliations, physical appearance, gender, and socialization experiences all inform the ways in which we perceive the world. Our realities are co-constructed in our “basic social interactions whereby we enter into the perceptions, attitudes, and values of a community” (p. 8). This theoretical perspective is often employed by researchers seeking to understand human identities and realities in the contexts in which such identities and realities are created.

2.1.3 Research Methodology

A research methodology provides the framework that allows researchers to decide how they will “frame a problem in such a way that it can be investigated using particular designs and procedures...and select and develop appropriate means of generating data”

(Schwandt, 2001, p. 161). Narrative inquiry, the design chosen for this study, is a methodology that is “applied in the creation, analysis, and reporting of life stories” (p. 171) and the basis for my choice of methods both for gathering data and analyzing data.

Narrative inquiry can be conceptualized as a form of qualitative research that “takes story either as its raw data or its product” (Bleakley, 2005, p. 534). It is through the stories humans tell that they construct meaning as well as impart knowledge. Questionnaires, surveys, and quantitative analysis of behaviors are not sufficient to depict the complexity of meaning creation in the telling of stories. Traditional quantitative approaches adopt a rational approach with the hope of achieving an objective description of the forces in the world. Conversely, when researchers employ the story metaphor, and take the story itself as an object of study, they acknowledge that people create order and construct texts within particular contexts. People co-construct their realities through the stories they tell about their experiences. Narrative inquiry acknowledges this understanding of human reality because it is based on the premise that humans are storytelling beings.

Employing narrative inquiry as a methodology involves soliciting narrative accounts from individuals in their natural language. Faircloth, Boylstein, Rittmen, and Gubrium (2005) suggest that narratives “rely on the ordinary and typical as a means of interpreting and giving meaning to everyday experience. The everyday usage of the taken-for-granted provides a foundation for the artful construction of meaning and practice” (p. 931). Clandinin and Connelly (2000) advise researchers employing narrative inquiry to “make themselves as aware as possible of the many, layered

narratives at work in their inquiry space...imagine narrative intersections, and anticipate possible narrative threads emerging ” (p. 66). They assert that any time one begins work on a research project one is beginning a new story. Further, they suggest that thinking about inquiry in narrative terms “allows us to conceptualize the inquiry experience as a storied one on several levels...in the construction of narratives of experience, there is a reflexive relationship between living a life story, telling a life story, retelling a life story, and reliving a life story” (p. 71). Narratives are inherently culturally bound, promote certain values and beliefs, and contribute to concepts of community and construction of identity, as such, they are an excellent way to foster an understanding of the rich and complex communication processes that continually produce and reproduce cultural understandings of health and illness, from the perspective of the survivors themselves.

2.1.4 Method: Conversational Interviewing

People co-construct their realities through the stories they tell about their experiences. Conversational interviewing acknowledges this understanding of human reality because it is based on the premise that all humans are storytellers. A conversational interview is a discussion between two individuals concerning a topic of mutual interest about which both are knowledgeable (Kvale, 1996) and was employed in this study to solicit narrative accounts from my co-researchers in their natural language. Natural language is both culturally and historically embedded; it is the language we use in our everyday lives. Natural language allows for richer and thicker descriptions of particular lived experiences, and is therefore well suited for unearthing “qualitative

descriptions of the life world of the subject with respect to interpretation of their meaning” (p. 124).

Conversational interviewing involves using open ended questions to move a conversation in the general direction the researcher needs in order to capture pertinent descriptions needed to address the research question. Such questions may include, for example, “What events or experiences since your stroke have had a significant impact on how you perceive yourself?” or “What personal, social, and relational understandings have you come to realize in the process of living this stroke experience?” Open ended questions allow co-researchers to decide what aspects of their experiences are most relevant to their perceptions of the phenomenon under discussion, however, the researcher maintains control over the general discussion; by asking leading, purposeful questions that keep the co-researcher focused on the topic of interest. Successful conversational interviewing is both a craft and a skill. Through “craftsmanship” (Kvale, 1996) the researcher is able to collect data that is rich, thick, and descriptive. These data are subject to continual analysis both while the interview process is ongoing as well as afterwards when it is transformed into text and thoroughly studied for emergent themes.

Conversational interviews can best be understood as construction sites for new knowledge (Kvale, 1996). Both the researcher and the co-researcher bring their existing knowledge to the interview, and in the process of discussing it, create new understandings of what the experience being discussed means. The interview is co-constructed in that “it is a specific form of human interaction in which knowledge evolves through a dialogue” (p. 125). Both researcher and co-researcher are gaining new

insights, creating new meanings, and developing new interpretations of the lived experience. The method of conversational interviewing is particularly well suited for this study because it is an effective means of soliciting narrative accounts from my co-researchers.

2.1.5 Method: Thematic Analysis

Kvale (1996) contends that the process of thematic analysis develops “the potentialities of meaning in a simple interview story into more elaborate narratives” (p. 193). Thematic analysis involves analyzing the data from the stories constituted with my co-researchers for meanings and common themes. It entails interpretation by the researcher of their own and their co-researchers narratives, with the researcher becoming a “conduit through which such voices can be heard” (Denzin & Lincoln, 2000, p. 23). Thematic analysis allows the human science researcher to articulate her perceptions of overlapping experiences and patterns of interpretation within the cohort.

Interpretation involves the process of locating meaning and understanding in the descriptive text and emergent themes of the co-researcher’s narratives. I concentrated on the perspective of each co-researcher, setting aside my preconceived notions about stroke, yet referencing my own experience with stroke, and allowing it to enter the realm of experiential possibilities. Thematic analysis informs every stage of the research process. To locate the commonalities of lived experience I had to interpret and re-interpret the meaning of my own narratives and those of my co-researchers. Thematic analysis compels the researcher to immerse themselves in the hermeneutic process:

continuously interpreting, reading, writing, and analyzing the data/capta for these emergent themes throughout the research process.

Since description provides the material on which interpretation is based, it was essential that the details of the interview interaction and self-narratives, complete with contradictions and ambiguities, be included in the report of the research in order to accurately reflect the experience and intent of my co-researchers. These descriptions were developed from audio taped narratives of lived experience co-created with my co-researchers in our conversational interviews. Analysis took place during careful and systematic examination and consideration of the audio taped data and the transcribed capta. During this final analytic step, the transcribed narrative was carefully studied for emergent words, phrases, and relationships that depicted in clearest expression common experiences of the co-researchers. These emergent themes were used to represent the co-researchers' collective experiences of the research phenomenon.

2.2 Participants

The focus of human science research is not on generalizing to a population, but rather on understanding the particular. As such, small sample sizes are an excellent way of gaining more comprehensive insight into and understanding of the lived experiences associated with a particular phenomenon, in this case, the experience of living through stroke. The number of participants one chooses depends on the number needed to achieve a comprehensive understanding of co-researcher meanings and themes, and, the actual number of participants is determined by whether or not the interviewer is getting new data from additional interviews. Kvale (1996) suggests that the study's purpose should

determine how many participants one ought to include, and suggests fifteen plus or minus ten as an appropriate number (p. 102). I interviewed five co-researchers for this study. After five interviews I perceived that I was no longer getting new meanings and themes, and decided that five interviews were satisfactory for my research purposes.

Given the research question I posed in this study, I specifically sought co-researchers who were eighteen years of age or older, had suffered a stroke, had never been diagnosed with aphasia, who self-reported that they managed their own affairs, and had completed physical therapy. These criteria were developed as a means of protecting participants from the possibility of exploitation. Individuals who were not legal adults were excluded as they could not give consent; individuals who had never suffered a stroke were excluded as they would not have the perspective of a stroke survivor; individuals diagnosed with speaking difficulties as a result of their stroke were excluded as they may have found articulating their stories difficult, frustrating, or upsetting; individuals who were not able to manage their own affairs were excluded, as the potential of diminished mental capacity would threaten their ability to make educated decisions about participating in research; and individuals who had not yet completed therapy were excluded on the grounds that the recent nature of the stroke event might make the recalling of their stroke experience particularly difficult.

2.3 Procedure

I used a combination of convenience and snowball sampling in selecting co-researchers. Both are useful methods of sample selection when a specialized population, such as stroke survivors, is sought. After contacting administrators at local health

organizations I was informed that since my research was not funded by the hospital, I would not be able to post flyers. In addition, since patient records are strictly confidential, local health organizations were unable to provide me with contact information for potential participants. As an alternative, I contacted organizations that provide social support services to community members, such as Parish Health Ministries, Love, Inc., Access Alaska, and Fairbanks Resource Agency to seek out stroke survivors who might be interested in participating in my study. I also, with permission of owners, posted flyers in public places such as libraries, churches, restaurants, and bingo halls, which explained the nature of my research and how any interested parties might contact me for more information. Additionally, I contacted the former leader of a now inactive local stroke support group, as well as leaders of stroke support groups in Anchorage, Alaska. I also informed my peers, faculty, and staff in the Communication Department at UAF of my study, and asked them to pass along my flyer to any potentially interested parties.

During my first contact (either via telephone or email) with potential participants, I introduced myself and my research project. The attached letter of introduction contains the content of what was included in these phone calls or e-mails. I explained that I was conducting research which examined people's experiences living with stroke. I also explained that my research would be qualitative in nature, and as such I was interested in hearing their stories about their specific lived experiences with stroke survivorship. I informed potential participants that interviews would most likely range from an hour to an hour and a half in length, but that I would not be adhering to any strict time limit. I

stressed that participation was completely voluntary and participants were free to withdraw from the study at any time during the research process. I explained that our conversations would be audio-recorded, and that their identities would be kept confidential via use of pseudonyms.

Four of these interviews with took place in the Department of Communication research interview rooms, 507E and 507F Gruening, and one in the home of my co-researcher. When I met with participants for the interview, I again repeated that participation was completely voluntary and that they were free to withdraw from the study at any time during the research process without penalty, simply by telling me that they wished to withdraw. Each potential participant received a thorough explanation regarding the nature of this research, and what it means to give consent. I ensured participants understood by reading to them the entire consent form, as well as paraphrasing its contents. I also gave participants the opportunity to ask any questions, and to address any concerns that they had. During this process I verified to the best of my ability that participants did not have diminished mental capacity by closely attending to their facial expressions and demeanor for indications of incomplete comprehension. Each participant verbally consented on tape before the interview began.

Throughout each interview, I asked brief, open-ended questions to draw out rich, descriptive narratives of my co-researcher's experiences. I asked my co-researchers about how they had experienced everyday life since their stroke. I also asked about the communicative events or experiences, personally, socially, and relationally, that led them to their understandings of life after stroke. I occasionally would include a personal

anecdote, or insight of my own to maintain the conversational flow of the interview, and to encourage continued dialogue on the topic. I also asked probing follow-up questions if I needed clarification or wanted to delve further into my co-researcher's train of thought. Though my concentration was on co-researcher narratives, I also observed their gestures, facial expressions, and kinesic grounding, as those lent meaning to what was expressed.

Each interview was digitally recorded, and immediately transcribed upon the interview's conclusion. The digital recordings were transferred from the recording device to my computer and password protected. All records of this study's data and capta will be kept in the University of Alaska Fairbanks Department of Communication for five years, after which time all collected information will be destroyed.

2.4 Researcher as Research Tool

In Human Science research, the researcher must acknowledge that she is also the research tool. As the researcher, I am personally involved in the research, the setting, and the experience of the study (Kvale, 1996), and therefore must "acknowledge my fingerprints," by which I am referring to how my life experiences inform my world view and inevitably influence my research. As a human scientist I perceive that research is "an interactive process shaped by personal history, biography, gender, social class, race, and ethnicity, and by those of the people in the setting" (Denzin and Lincoln, 2000, p. 6). The researcher must be reflexive throughout the research process, and communicate that reflexivity to their readers. Communicating that reflexivity to readers entails providing an account of how personal interest, bias, personality, and value orientation all influence the research that has been conducted.

The experience of life after stroke is of particular interest to me because, as a child of a stroke survivor, I would like to better understand the impact stroke has on the life of survivors and their families. My father's stroke has had a dramatic impact on the dynamics of my family, causing me to wonder about the stroke experience of other survivors and the understandings they gain about self and others in the process. As a Communication scholar, I perceive that the most effective means of gaining such an understanding is through stories told in the natural, everyday language of the survivors themselves.

As the daughter of a stroke survivor, I have already constructed meanings for the stroke experience, and as a consequence, I may favor interpretations that most closely align with the construction I have created. My personal experience with stroke will impact the ways in which I have interpreted the narratives of my co-researchers. As a twenty-five year old, white American female, I am also likely to be much younger than my co-researchers, which may impact how trustworthy or credible they found me, which in turn affects the nature of disclosure during the interview. Further, since I personally have not suffered a stroke, co-researchers may be wary about discussing their experiences frankly and honestly with an 'outsider.' Additionally, although I am doing my graduate research at the University of Alaska Fairbanks, I am originally from, and have spent most of my life in Massachusetts. I perceive these cultures to be markedly different, which increases the potential of developing divergent meanings from those of my co-researchers. These aspects of my identity impact both how I interact with my co-

researchers, and therefore the nature of the narratives we co-construct, as well as how I have interpreted the experiences and insights of my co-researchers

Chapter 3

Narrative Perspectives

In the previous chapter I outlined the choices I have made at every level of the research contexture. My intent in doing so is to allow the reader to best understand how I have approached my research, and therefore better determine its quality and merit. In this chapter I will describe for the reader my interpretation of the interviews I have conducted with my co-researchers. My approach in describing these interviews will first be outlined to provide context and clarity. Interviews were conducted with a digital recorder which I uploaded onto my computer and transcribed using transcription software called *ExpressScribe*. I transcribed the interviews shortly after I conducted them while initial impressions, opinions, and observations were still fresh in my mind.

Silverman (2001) proposes that “interview data are never simply raw but are both situated and textual” (p. 288). During the transcription process I not only recorded all dialogue, but also my recollections of both my own and my co-researchers non-verbal behavior, such as a smile or a grimace or noteworthy hand gestures. The non-verbal is the context in which the verbal is interpreted, and as such it is important that I acknowledge non-verbal gestures that I perceive contradict, reinforce, or add clarity to what has been said. The reader must also have access to my perceptions concerning what my co-researcher and I have discussed. The way the following interviews have been described is a co-construction of both my own and my co-researcher’s understanding of the stroke experience. As such, in the description of these interviews the back and forth exchange of ideas as voiced by both co-researcher and myself will be present.

3.1 Prudence's Conversational Interview

I meet Prudence, my first co-researcher, for the first time when she arrives at my office for the interview. She is a woman in her seventies who suffered a stroke twelve years ago. She arrives in a wheelchair, and while it appears that her range of movement is quite limited, her face is animated and her voice lively and expressive. I read her my consent form and ask if she has any questions; she does not. I ask her if she understands the consent form as I have explained it, and she replies, "Alright. I am perfectly happy to be in this study, and I do understand." I begin by asking Prudence to describe, in as much detail as possible, events or experiences since her stroke that have had an important, or significant impact on how she perceives herself. Prudence pauses for a moment then begins by describing her life just prior to her stroke. She had been teaching at University of Alaska Fairbanks for the previous 30 years, and was up for tenure. My co-researcher describes this time as very tense and stressful, because it coincided with her breast cancer diagnosis. It was at the end of her chemotherapy treatments, several months later, that she had a massive stroke which left her in a coma for three days and completely paralyzed her left side.

Prudence reports staying in Anchorage for short while after her stroke, an experience she tells me was "not very pleasant in general because, they basically treat you like a five year old, if not younger." She explains why she feels this way by describing a situation in which one of her health care providers was having difficulty running a computer program used for medical testing, and Prudence, who asserts that she has been involved with computers since "main frames back in the 1950s," offered advice

that was completely disregarded. She recalls that “she [the technician] was trying to get this, program up, and [as] she was having me do it, I said something about you could do this a lot more easily if you just did this, this, and this.” But the woman to whom she was offering advice “said no, you have to do it exactly the way I tell you.”

Interested in hearing more about her interpretation of this situation, I ask if she perceives that the technician did not value her opinion. “I suspect I’m being harsh” she replies; “I suspect it was that she was not used to computers, she knew how to go to that program, period. And she didn’t want to hear anything else ‘cause it would confuse her.” My co-researcher mentions that her husband David, who is also a computer programmer, later entered the room and offered the technician similar advice “and she did listen to him. But she obviously, at that time, wasn’t listening to me.”

Prudence discloses another story to elaborate why she feels negatively about her Anchorage experience. “The first, real communication I had was one I didn’t want, really.” When I look at her expectantly she continues, indicating that the doctor who was monitoring the in-house procedures came to see her and said, “the first thing you’ve got to do is face the fact that you’ll never walk again, and I understand you want, you teach, and you want to go back to teaching. You will not be able to do either of those, ever.” Recalling her reaction, she tells me “I decided, lady, you don’t know me. [She] made a general, generalization, without any knowledge. I *have* taught, and walked.”

Remembering another event, which she concedes she may have dreamed, my co-researcher talks about rewiring a machine next to her bed that had been wired incorrectly. She articulates that in doing so, she “surprised them [the technicians] to no end, but they

weren't upset about it or anything, and so after that they just they listened a bit more." I ask her if she regards their listening as a form of respect, to which she replies yes, "after I did the rewiring, they decided maybe there was more up here," she points to her head, "than they thought." Hoping she will elaborate, I ask her if she perceives the initial response she gets from others is that she is incapable. She affirms, concluding that "the people who are doing the testing, you see, have no idea what level is left." My co-researcher expresses gratitude because her stroke did not affect her cognitive functioning or her ability to speak. Unsure I have an understanding of her meaning, I am about to ask her to explain what she means when she changes the subject, and begins discussing her medical history.

Curious as to how Prudence perceives her medical history to be significant in our discussion, I do not interrupt. She explains that she was born a twin in 1930 "with what is today referred to as cleft lip, cleft palette. In those days it was just called hare lip." She tells me she is amused by a family legend about her from the day she and her sister Samantha were born. My co-researcher recalls that her mother and her sister both were "having trouble" so the nurses, "put me on a shelf in a box and just left me there" while they worked on her mother and sister. She then tells me that the nurses decided to take both her mother and her sister to different rooms for other treatments when "one of the nurses looked over and said, this one's still alive, you gonna take her too? And so, they took me with them. Otherwise they wouldn't have." I am about to ask her why she believes that they would not have taken her with them, when she continues,

and so I'm now, from the point of view of the family, I'm the one who fights back and survives. So when they, when the lady tells you you're not going to walk again, you're not going to teach, and all that did was push the magic button and said yes you are.

Prudence starts talking about her experiences after she was discharged from the hospital in Anchorage, and had started in-patient rehabilitation in Fairbanks. She remembers her time in Fairbanks more favorably because by then she felt her condition had improved a great deal. She explains that "there was a different atmosphere entirely. I had a good time, yeah, I got to know them [the medical staff] very well." She informs me that she did learn to walk, and did later go back to teaching. "So, kind of what you see is what you get," she adds.

Prudence discusses the steps her husband David took while she was still in the hospital to make their house more accessible for her. She recalls how he cleared out the guest room for her so she could be on the main floor, and remodeled the bathroom so she could get in with a wheel chair. Prudence describes him as an amazing caregiver, but admits that she did not like that he had to do so much work for her when she returned home, contending that this was "because I'd been too independent before. We were both professionals, and he did his thing and I did my thing. And I couldn't drive, or anything, so anytime I wanted to go anywhere I had to get him." She says he is very busy with his work as a field biologist, and addresses a specific occasion when he was invited over to collect specimens in forests in Russia. The mention of an invitation to Russia prompts me to ask her whether he travels often. She tells me that he still travels in the summer,

but that it is different now than it was before her stroke. “Before the stroke it was not a problem at all, because if he was going, for example, to Russia, he just went to Russia! Period.” Prudence adds that “he still goes out in the summer. But now when he goes in the summer we have to, I can stay by myself, but it worries him too much. So, um, we line up somebody to stay at the house with me. Which is fine.”

Interested in where she will direct the conversation next, I sit quietly and allow her to continue. My co-researcher starts to outline their daily routine for me. He cooks dinner, takes care of the house, and “he does cleaning, but it’s not the same as if I were, but it’s liveable. And I don’t give a damn.” I laugh at her choice of wording, and she smiles in response, continuing, “so we do have a, uh, in fact [a] quite nice routine.” Prudence explains that he makes breakfast, then he wakes her up and they eat together, and then he goes to work in his lab, which is attached to the house. I think it is a good idea that his lab is attached to their house, in case she ever needs help. I allude to this thought by saying “so he’s close enough,” to which she replies, “I’ll tell ya we have a buzzer system he put in, so if I want him for whatever reason, I can just push a buzzer.” My co-researcher informs me that he is good with electronics, carpentry, and making furniture, which has come in “very handy.” She mentions that he built a skyhook over her blue recliner which allows her to stand up by herself. She tells me that once up from her recliner she can get around the house without assistance, “I just, I furniture walk is what they call it. Anything I could do to get around, I do it.”

I realize that I have heard very little from Prudence about her experiences with people other than health care professionals and her husband. So I ask her how her social

life has changed, and she informs me that “the people who were my best friends, women, that is, before the stroke are still my best friends after it. They come visit, they take me places, and we do all kinds of things.” She recalls one friend in particular who took her to water aerobics therapy once a week for a year after her stroke. “That was magic. Because I don’t swim, but it allowed me to walk and balance and all, by myself, without having to depend on anybody else.” She details how her friend would hold her hand and they would exercise in the water, disclosing that this is how she had kept herself in good condition, but that at present she is in bad physical condition. She indicates that the cold weather prevents her from getting exercise. She adds that the cold weather is also preventing her from driving, clarifying that while she can drive, “with as cold as it was, David requested that I not do it, until summer. So he takes me everywhere right now.” Prudence tells me she thinks this is reasonable, and explains that her husband is “perfectly happy to take me anywhere I want to go, like bringing me here.”

Prudence starts talking about her social life again, informing me that she also has a friend who will take her out to lunch or dinner if she wants to go, and who will come get her whenever he goes downtown. She explains that she “gets out quite a lot,” and that:

when he’s [David’s] away, uh, even if it’s just for a weekend, one of my friends, I have instructions that I am to call her in the morning when I wake up, and if I don’t call by a certain time she’ll call me to check, so I’m covered. Very good support group.

She also informs me that her twin sister came up from Atlanta following the stroke to help her and her husband through the first few months, and recalls that her husband was going to take her to Atlanta to visit her sister the following summer but was unable to go, “and so I called the airline and asked if I were in a wheelchair, could I go by myself? And they said ‘oh yes’ we’ll wheel you around, flight to flight and all that. And so I made all the arrangements and then I told the therapy folk- I’m going to Atlanta anyway.” I laugh at the sing-song tone she adopts when recalling what she said to the “therapy folk.” She reports that she made it to Atlanta without any trouble, and has been going there once a year ever since.

I ask whether she feels that her sense of identity has shifted since her stroke or if she feels that the stroke has reinforced who she is. She tells me that “it’s [been] reinforced,” adding “I don’t know why particularly, but maybe family legend’s true or something. I have a strong, strong sense of identity.” She contends this might be because she was born a twin, and “growing up as a twin everybody does things in pairs, ya know. You’re always part of that person. You’re not you and Samantha. So I think I probably grew up, uh, making it obvious that I was Prudence.” Since she claims no identity shift, I ask if she perceives that anything in her life has changed since her stroke. She explains that she is “a little limited, in the sense that, for example, in this weather if David’s not home, I’m stu, stuck.” Correcting herself, she says, “well, not stuck, I have my car, it’s there in an emergency, I can leave.”

I am wondering if she has ever been “stuck” before, and am about to ask, when she tells me that she had to call 911 once. Laughing to herself, she quickly clarifies that

“it was fine, it was just perfect, but I don’t need them. This was a freaky thing that happened.” She had dropped her cane, and when she sat down to pick it up, she did not have the strength to stand back up. She informs me that she had her husband’s cell phone in her pocket and was therefore able to call 911. She always locks the door when she is home alone, so the E.M.T.’s had a very difficult time finding a way into her house. She recalls that they “just had a hysterical time after that,” trying to figure out how these men could get in to help her, which they eventually did, through sliding doors in the back of her house. Hearing her describe the situation as “hysterical,” I ask her if she found the situation entertaining. She nods her head slightly in agreement and repeats the word “entertaining.”

Prudence starts talking about her years teaching courses such as chemistry, biology, physiology, and endocrinology at universities. She explains that she taught two classes “full of kids, and I guest lectured, and uh, [in] micro physiology and steroids, because I was, that was my research many years ago when I got my doctorate. So, I have [a] wide range.” My co-researcher relates that it has been good that she has not lost any of her cognitive abilities because of her stroke. She mentions an acquaintance who had a stroke long before she did, who suffered many different cognitive impairments and almost committed suicide before he was stopped by friends. She explains that they took him out to a horse facility, put him on a horse, led him around, and told him that they would be doing the same the following day. His friends were able to get him interested in horses and “then he could just go out there by himself because there were always people there. And he rode, ya know, groomed horses did all sorts of things, he got

interested in something, so uh, it saved his life.” Prudence informs me that the first thing she wanted to try after the stroke was reading, “‘cause I knew, I wouldn’t have committed suicide, ‘cause I’m just not that way, and uh, I would have found something else, but I did want to read and I, David and I both, are speed readers, and we, our house is filled from floor to ceiling with materials.” Hoping she will elaborate, I ask her if her cognitive abilities were really important to her. She explains that her husband’s IQ is “mammoth” and while hers is not mammoth “it’s up there,” and that everything they do is “oriented intellectually” so “if the cognitive hadn’t been there I would have probably ended up in some kind of nursing facility or something.” She adds that her daughter had an IQ of 165, and digresses from there, talking for quite awhile about her daughter. I ask if she is still close with her daughter, and looking slightly startled, she tells me that her daughter was killed by a drunk driver when she was seventeen. When I offer her my condolence, she brushes it away, explaining:

It’s part of life, it’s, that’s one thing I think that was a very good thing about the cleft palate and all that. You don’t go through this routine that people go through where [they ask] why did it happen lord, why me, all that. Things. Just. Happen. So when she was killed we were clobbered. But we didn’t have that long routine of, uh, why us? What did we do wrong? None of that.

I notice that she was speaking for her husband as well, so I ask her if she thinks that he has a similar attitude and she replies that she does.

My co-researcher indicates that she “got into” horses after she got her daughter one. Her daughter had been taking lessons for about a year when she announced to her

husband one night, “I’m getting me a horse, and he said, well ok ... it’ll be a friend for the other horse too.” Prudence talks to me about taking riding lessons and spending time with the horses, and that “until the stroke we had horses, it was too hard on David.” Wanting clarification, I ask her if she is referring to taking care of the horses. She answers, “yeah, he’s, he’s, doesn’t like horses.” I ask what she did with her horses after the stroke and she explains that one had already passed away of old age, and the other one she gave away. I ask if she misses them, and she tells me that she does not visit “because I miss ‘em too much. Uh, I enjoyed every aspect of it- cleaning the barn, their paddocks and everything. I just, it’s really nice, when you’re out cleaning the barn [because] nobody bothers you.” Here she changes the subject, telling me that she had “generally speaking just a very busy life.”

I comment that it seems that she has a really good attitude, and she tells me that she read an article which suggests that whether one’s attitude is positive or negative depends on the side of the brain affected. I ask if she thinks that is why she has a positive attitude and she contends that she was “amazed, because I had, or everybody I know has commented on ‘you’re not letting it affect you at all!’ And I said, no, where I can do things I will, because that’s where my religion comes into it.” She explains, “God gave you such a fascinating world, it’s so interesting! And, ya know, he gave you this, and you’re supposed to embrace it, take it, use it, learn about it.” She asserts that this was her “attitude in general. And it still is, and I suppose it could currently be generated by the solid brain, but it doesn’t necessarily have to be.” She tells me “with the hare lip and all, things were not great when I was young, but shoot, it taught me a lot.” She also says she

attended Yale graduate school when it first became co-ed and describes that experience as challenging, but she tells me that she “made it and got my Ph.D, in physical chemistry. At Yale.” We talk for awhile longer about her experiences in graduate school and as a teacher. Sensing at this point that our conversation is not opening any new issues, I thank Prudence for her participation and end the interview.

3.2 Julia’s Conversational Interview

I meet my second co-researcher through a mutual acquaintance who told her about my study. Julia arrives at my office and we walk to a private meeting room in the back. She uses a walker, and I notice that it takes her a very long time to move along the corridor to the interview room. She looks to be in her fifties or sixties, although I am a poor guesser and I never ask her for her age. She has a very pleasant demeanor and an easy smile, appearing at ease throughout our conversation. I read her the consent form and ask if she has any questions; she does not. I ask if she understands the consent form as I have explained it to her and she replies, “Ok. I do understand it, and I’m a willing participant.”

I begin by asking Julia to describe in as much detail as possible events or experiences since her stroke that have had an important or significant impact on how she perceives herself. My co-researcher begins by telling me what her life was like before her stroke. She reveals that “before the stroke, I’m a mother of four, my husband, uh, works at Eielson, and I was the typical mom, the taxi driver, the coach, the ya know, all those areas, just busy busy busy.” She and her husband were in the process of building their retirement home when she noticed that she could not walk, “and the next day, um,

couldn't move so it was diagnosed with a stroke." In response to my question, she tells me that it happened five years ago.

I motion for Julia to continue, and she tells me that after her stroke "the whole, my life just shifted," and that even though she has made a good recovery physically, "it really changes; you're a different person after the stroke. I could not jump back into the roles of meals on the table, of taxiing people to and fro, and at first the mental part I think was the hardest thing." My co-researcher informs me that she felt like she was "an intelligent person," but did not feel that way after her stroke. After a stroke, "you're much slower, you have to think about everything," just walking across the room requires thought. Julia says you have to "remember to put your foot here, ya know, not to curl a foot. You have to, um, I have to have so much, uh, mental process to do everything." She adds that she also, "was a chatty person, and very fun loving, and now its, um, everything has to be thought about, and it's a very much a mental process to even move." As an example she tells me that

you can't, for instance, go in a crowded room and just visit people, you've gotta think, where can I stand where I won't fall, and then you, I just have to be really careful and be sure that I'm saying the right thing, because oftentimes, um, something will come out not like you were thinking it.

Julia comments that about two weeks after her stroke she started to regain speech, but that her words would "come out not at all what I was thinking. It's like, woah, this is really crazy." She mentions a funny story when she was in the hospital and could not get out of bed. She needed a bedpan, but when she asked for one, she said "could you get me

the bird pan?” We both laugh, and she clarifies that she knew she was saying the wrong word, but could not make herself say bedpan. She also went through a period when she first got home where “it was totally out of character for me, but everything came out a cuss word.” She could not control it, “these crazy things would [just] come out.”

Julia divulges that she does feel that she is a different person now, and that she also thinks her stroke has affected the dynamics in her family. She comments that she “was the, let’s say the pillar of the family, and now I just can’t do that anymore, so that is, that’s hard. And uh, I was just totally happy.” She adds that “you do become a different person, and um, while it’s great to recover, you do miss the old person too. Ya know, I wanna do the things I used to do, but it’s, some things are not possible.” I ask her what things she does differently now than she did before and she notes that she had a lot of hobbies before, and that she “loved to read.” She would read anything, “any kind of book, a magazine, just reading, and now I have no interest.” My co-researcher notes that there is also a difference in her abilities now, “like I can read and it’s like, what did I just read?” adding that her memory was also affected by the stroke: “That is a big area, is the memory, uh, like somebody in the family will say, ‘oh, remember when we did so and so?’ And it’s like, no. I have no memory of it.” She tells about an occasion the previous week when she was talking to her brother and he asked her if she remembered the first time he came to Alaska to visit her, “and I said, you came more than once? Ya know, there’s just no, no memory of that all,” although she adds when people start to describe for her what she has forgotten, her memory often returns. Julia explains that “it’s in there; you know it’s there, but when will it come out? Maybe not when you want to

recall it, and you've gotta have a prompting." She could be watching a movie with her children and "maybe the kids will bring it again in a week and say, remember this mom? No, I don't remember it. But as we watch it, oh yes! I remember, but I couldn't tell you what's coming." I ask her if she finds this frustrating and she says that it is. "You can get really frustrated" my co-researcher explains that she is "a much quieter person, because you do have to, really concentrate to do everything. Um, I'm just not as forthcoming as I used to be." She tells me that she finds this very difficult to handle.

However, Julia says that there are "positives" too; she reports that she thinks about things differently now: "The importance of things now has shifted, like a clean house now is not a big deal, but it's how you treat people." The stroke has made her "have a real, um, realization of how important relationships are," and that after a stroke "you begin to maybe not be so hasty to do things, but to really give a lot of thought to things." She pauses for a moment, then tells me that she thinks that "in a way I'm a better person now, through this." I think her observation is interesting, so I ask her why she thinks she is a better person. Her response is that, after a stroke, "you put the emphasis now more on what is really really important and, and I think that's good, I don't, ya know, I don't know that I would even go back to the way I was before." This really catches me off guard, because I never thought I would hear a stroke survivor say that, given the opportunity, they would not go back to how their life was before their stroke. "Really?" I say, and she tells me it is true. I want to know more about why she thinks she is a better person. now, so I ask her if she thinks she is a better person because she is more careful with her words. She explains that since her stroke she appreciates

“things” a lot more, and adds that she does not “see life now as getting through each day doing silly little things, worrying about this or that. Now I’m much more reflective I think, and I do think I’m a better person.” Laughing to herself, she admits that she would “like to get up and run around again” but asserts that after a stroke “you do think more about what is important.”

I ask her if she thinks a stroke forces you to slow down and she tells me it does. I remark that “my Mom said the same thing about my Dad after he had a stroke--that he’s a better person now.” Julia replies that the stroke “sort of put the brake, ya know, when you’re laying there after the stroke, you don’t know if you may have another one, and live, or not.” She indicates that it has made her more careful, and “that’s a good part of it.” I tell her I think that is a good attitude, and she laughs, “you sort of have to get that attitude afterwards to really be successful too, ya know?” I nod in agreement, and she explains that it has been five years since her stroke and she still feels like she is in therapy “when I do anything, it’s like, ok, can I go one step further this time? Can I walk, uh, 20 steps further on this trip? [I am] always like ok, you’ve gotta improve, and I think that I’m real careful now to maximize everything.” Although she says that it is frustrating “if there’s something that you can’t do that you used to do, it’s like, uh oh, I can’t stand that. But you just have to keep working at it. And take uh, little steps are giant steps to me now. And every little step just like, oh, woah, I did this or that.” She stresses the importance of keeping “the attitude up of, ok, maybe I can’t do it, but I can work at doing it and get as far as you can.”

Julia comments that she also thinks it is very important to have a lot of contact with people after a stroke. She explains that “sitting for long periods of time alone with no, that is not good, that is just not good at all. I want a lot of human contact.” I ask her whether she thinks that is unique to her, or a part of the experience, and she answers that she thinks it is part of the experience. She recalls that when she was in rehab, that was “sooo important to everybody. I don’t know why, but its real important to have lots of input, lots of contact.” She adds “what maybe would’ve been just a minor, hi and goodbye kind of relationship [before the stroke] is now more than that, it’s like, lots of contact on the phone with people. And I, for me that’s really important.” I ask her if contact with other people helped her a lot and she says that it did. She explains that it is important “to get out and about,” because it helps her “to be part of the community again.” She gives the example of her son calling her and inviting her to watch the basketball games for the team he coaches,

it’s like, come on to the game, mom, and that is, it is really good to get out, and still feel like you are not, um, a disabled person that just has to stay shut away. I think that is just not healthy at all.

I ask her if she had felt like that, like she had to stay shut away, and she contends that she did for the first year or so, when she would “just spend hours crying about, because I was out there, and then to suddenly be, you can’t drive.” She explains that for a period of time she was not able to drive and that had been her greatest “barrier.”

Julia says that she also was in a wheel chair for a while and that “that was one thing I did want to talk about, is the attitude of people.” She indicates that she thinks

people ignore her, “when in the wheelchair, especially, but even now.” My co-researcher recalls going to an appointment and everyone talking to her husband instead of her. She comments “they wouldn’t even look at me and I’m like, ok, wait a minute, I’m here. I can answer that!” She remembers an occasion when she was leaving a monthly appointment with her nutritionist, when her nutritionist approached her husband, and told him “would you give this report to her, and tell her to do this.” She reports that her husband told the nutritionist “no, you need to tell her.” Julia explains that it is “very, very, ah, just maddening to not have people talk to you, and I can talk, and I can answer questions, so I’m wondering why, especially if you’re in a wheelchair, do people not talk to you?” I ask her if by “people” she is referring to people who work in hospitals or to people in general. Julia affirms that it is true in general, “but especially on medical appointments.” She reiterates that her health care providers will talk to her husband instead of her and “it’s like don’t they think that I’m capable of answering.” When people “see someone in a wheelchair, or with any disability, that doesn’t mean you should not communicate with them.” She laughs at that, and says she finds this “now, even now, frustrating.”

Another frustration she mentions is that for “about two years [I] couldn’t control my tears. Could be anywhere, at any time, it would not be [for] a particular reason, and I would just burst out in tears.” Seeking clarification I suggest that she was not actually upset when she would start crying. She responds that she was not upset, but “tears would come any time and you couldn’t stop them.” Julia recalls that she would be “talking to a friend and here would come the tears, and [they would] not have a clue why I was crying,

so it was, um, that was really frustrating.” She mentions a day in therapy when she started crying halfway into her class and could not stop. She excused herself and went to the restroom, but she could not get the tears to stop. Eventually a nurse “came in and said, ‘stroke victims do this.’ She said ‘don’t worry about it, it’s ok.’” I ask her how people usually react to this uncontrollable crying and she replies that they “don’t know what to do,” and that most people think “oh, what’d I say wrong to her.”

Sensing that Julia has run out of things to say on that subject, I ask her what personal, social, and relational understandings has she come to realize in the process of living the experience of stroke. My co-researcher explains that it was very difficult for her. “I was the home schooling mom, the just do everything mom. That all changed with the stroke” she explains. The child she was home schooling started over at the public high school. Julia remarks that she feels “especially with the kids that they remember the mom who did everything. I don’t even cook a lot now. And I’ve tried to teach the kids how to do a lot of cooking, but I want the old mom back, in a way, for them.” She says that “they say they’re ok” and that actually, she thinks they have dealt with her stroke better than she has. She repeats that she “would like to have the old mom back,” and adds that she thinks her husband has also dealt with it better than she has: “he’s a high energy person, so he does the laundry now, he does the things, so many, that I used to do. And he’s ok, but again it’s, I would like to be that person.”

I ask her if she feels guilty because she can no longer do these things, and she tells me that she does not think it is fair to “the guys to say, oh, would you wipe the tops of the windows off? You know, you can see, but you can’t always ask people to do *your* job.”

She comments that she does not like this at all, noting that “you can also sit and look at the dirt, but you can’t do much about it.” Julia reiterates that she thinks her family has dealt with it better than she has, which prompts me to ask her how they deal with it. She responds that they are very helpful; “they really hover around me and help. They’re like do you need this Mom, do you need that?” My co-researcher explains that her family has been great, and that it “would be really hard without a supportive family. Because I live in my own home, ya know, somebody’s transporting me if I’m not driving, and so... it’s been, it’s been easy because I have a really supportive family.” She indicates that “without that, it might be a whole different story. It would be.”

I ask if, in addition to a supportive family, she has supportive friends. Julia responds that she does, and that “they have really really done a fantastic job.” She pauses for a moment, then continues, “I think they worked harder at being friends. I mean, they really do still put in the time to make sure, you know, a birthday or something is a big deal.” My co-researcher indicates that her relationship with friends has changed in that she can no longer do a lot of the projects they used to work on together, like making scrap books. She remarks that “it slows you down in some areas, but then we spend more time visiting, so, um, I would say definitely the friendship bonds are thicker now,” and that everyone around her thinks life is more special “because I was a young mom, out there doing everything, and now everybody’s like woah, look what happened.” She also tells me she has “noticed my friends do things now, um, maybe more earnestly, and are more appreciative, just by watching how it does change you.” I clarify that she thinks that is because it could happen to anyone at any time, and responds,

to be building a house and, ya know, doing all that and then suddenly it's like, no that's gone now, and to think, wow, you wake up one morning and you've had a stroke! I was in a coma for three days, and so, you really feel like you're maybe not going to live. And then, but then I feel like I made a miraculous comeback. And that there is always hope, too.

I ask her if she was going to give advice to people about interacting with stroke survivors, or if she wanted to give people insight into the life of a stroke survivor, what she would say. Julia replies "don't treat them like they are disabled, be totally normal." She reports that she "just told one of my kids the other day, if I have another stroke, you come and you talk to me as normal." She tells me that when she first had her stroke, she could hear and she knew exactly what was happening but everyone was "different" to her: "I just want 'em to walk up, well they, my doctor, who is also a good friend, would stand at the foot of the bed, and just talk to my husband. He and my husband would talk like I wasn't there and its like guys, I can hear you." I ask if she felt she was being ignored, and she agrees, "that's right, you're ignored, and everybody's just buzzin' around and you're, it's just like you're not there." She tells me that she noticed with other people "who had a cane, or a wheelchair, that, and everybody talks very simply to you. It's really, it's pitiful. And I do see that with the other people too. Um, and I don't even, I hope I don't do that to other people with disabilities." I ask if she thinks her stroke has opened her eyes, and she answers yes, he tells me that she is "sure I did this too, before the stroke." And that she thinks she has "a lot of insight now, and a lot of empathy, that I didn't have before."

I ask her if there is anything else she wants to talk about, and she replies that “pretty much covers it.” We talk for several more minutes about life after stroke, and I tell her about how my Dad is doing. I perceive no new concepts emerging from our conversation, so I thank her for her time and end our interview.

3.3 Michelle’s Conversational Interview

I meet Michelle for the first time when I arrive at her home for our interview. The first thing I notice is that she does not look like she has had a stroke. In her early seventies, she moves quickly through her house, doing what I suspect is some last minute tidying up. She offers me coffee and invites me into her living room, where I choose a seat directly across from her. I read my consent form to her, ask if she has any questions, and she shakes her head no. I ask her to state for the audio record that she is a willing participant, and she answers “ok, yes, I agree to participate and I do understand it.” I inform her that I will make a copy of my thesis available to her if she is interested, and she responds that she “would be very interested.” I ask for her email address so I can send it to her, and she spends the next few minutes flipping through her rolodex trying to locate it for me. She gives me the address and then settles back into her chair.

I begin our interview by asking her to describe in as much detail as possible events or experiences since her stroke that have had an important or significant impact on how she perceives herself. Michelle tells me that she thinks one of the “most important things was the loss of self-esteem, and, um, and a feeling of helplessness, where before I was always, um, willing to do things, and adventuresome.” She mentions that she “drove in the winter, didn’t bother me at all, and after this happened it was such a devastating,

blow to my, um, self sufficiency that I felt that everything had just been taken away from me.” Michelle informs me that she wants to give me “a little bit of background.”

Clearing her throat, and shifting in her seat, she begins “it happened, uh, I was 63, and, uh, in October, and I had gotten up in the morning and when I walked out to the kitchen I discovered I wasn’t tracking right.” I look at her quizzically, unsure of what she means by tracking, so she explains that her “foot was not...pointed straight ahead.”

Her brother-in-law had had a stroke about 3 years prior, so her “first, question was I’m not having a stroke am I?” She recalls going to pick up her coffee pot and almost dropping it, so she woke up her husband and told him “I don’t know what’s wrong, but something’s wrong and I don’t know if I’m having a stroke, or what.” She was planning to visit her sister in Dallas “in um, ‘bout five days, and I just could not believe that I, instead of visiting her, I was in the hospital, and having the same thing happen to me that had happened to my brother-in-law.” Over the course of the next three days she recollects becoming completely paralyzed on the right side of her body. She could not write her name, or “even raise my arm without reaching over,” demonstrating lifting her right hand with her left, “and bringing it, and the same with my foot in the bed, I would take my foot and bring it over.” She describes spending ten days in the hospital, five of which were in the I.C.U., followed by nine months of outpatient therapy: “it was a long, slow process back.”

My co-researcher reports that at the time of her stroke, the hospital where she was treated did not have “that, stroke shot that they can give you that, um, [you have to get within a] three hour window.” I know what she is referring to, because when my dad had

his stroke, he got that shot, and it stopped the stroke's progression. Michelle reiterates that "they did not have that at the hospital," which meant she "just had to get, everyday I was a little worse than the day before, for three days, which was terribly devastating." She recalls that when she first got to the hospital she "could scribble my name, but I couldn't, and I could walk" but "within three days I couldn't do anything." She contends that "they just could, watch it, ya know" and that "there wasn't a whole lot that was done except to see how far down I was gonna go and then try to bring me back." Again, Michelle calls the experience "devastating." She divulges that:

going from being independent and planning trips and things like that, and going down to see my sister in Dallas, and, and her husband, to being completely helpless, um....I'd gotten a lot of things back now, but I still have that feeling, like I'm very vulnerable. Where before I never had the feeling of vulnerability.

I ask her how long ago she had her stroke, and she informs me that it happened eleven and a half years ago. "So it just doesn't go away?" I suggest, referring to the feeling of vulnerability. She tells me that "it doesn't go away," and adds "and I'm a lot more timid about things." She explains that she no longer drives in the winter, and that, "there's no physical reason I can't, but I don't have the confidence, my confidence just went." She remembers that for about a year after her stroke, she would not "even try to drive." She mentions her doctor asking her why she was not driving, and she told him it was "because I don't feel self-confident yet." Michelle remarks that she was a good driver, "I mean it wasn't that I was a little, timid, little old lady or anything, I was a good driver. But I just didn't feel confident."

My co-researcher notes that she has also lost a lot of her memory, and that she still does not “have some of the things back.” She “can’t process the things as quickly” and she “usually [will] have to tell people to say it two or three times, or go very slowly, because I say I can’t copy it that fast.” People will tell her “oh, you’ve got everything back” but she informs me, “I haven’t gotten everything back.” Michelle gives me an example of “something very simple, that people don’t see, that to this day really bothers me.” Because “that right foot is still not, uh, a hundred percent,” if she carries a cup with liquid in her right hand “I slop the coffee, or I slop whatever it is, so I can only bring one cup at a time, and it has to be in my left hand ... it’s a little thing, but it bothers me. Even to this day it bothers me.” I ask if it bothers her that other people see her having difficulty, and she disagrees, suggesting instead it is because “I should be able to do that.” She recalls being in her kitchen the previous night with a shaker in her right hand and “I flipped it, right out of my hand. It’s always the right hand that does that, because the right hand doesn’t work a hundred percent.” She informs me that it fell to floor and spilled all over and that she “get[s] upset, way beyond what I should. Other people drop something and they say ‘oh darn’ and they pick it up.” However for her,

it’s a sign of, you still aren’t back where you should be. There’s nobody here but me, but I just blow my top, and I think darn! You know, here I am again, can’t even hang on to a simple little shaker, and it flipped out, and I had a mess on the floor, and it’s this darn stroke.

She tells me that this upsets her much more than “in a normal situation,” explaining it is these “little, everyday things” that “people don’t notice, and they say, ‘oh, you’ve

completely recovered from your stroke.’ But I haven’t. And it’s these little things that people don’t see, that to this day get me terribly frustrated.”

I ask Michelle if she still compares herself to how she was before she had her stroke, indicates that she does. She cannot run anymore, and when she tries she can only hobble, “and I used to love to run up and down the drive to get the paper, or whatever, and the first time I tried it, it was a hobbly-hop type thing.” To this day she still can’t run, “and I grieve because I’ve lost it. Not that I always run up and down the drive, but it’s just knowing you *can’t*.”

Michelle thinks for a moment, then remarks that she also was unable to write for a long time: “I had to sit there and take a pen that had a big, um, piece of foam around it. And I had to try like kids used to years ago in penmanship? Make a circle. Well my circle was like this,” she traces a crooked shape in the air, “and it was about that big.” She cups both hands together to make a circle the size of a soda can. My co-researcher informs me that she also had to “write my name, *over and over and over*, and I would get so upset, I told my husband one time, its like I’m two years old again, and I’m trying to learn to write.” She remembers another thing she could no longer do after her stroke: “I didn’t know how to tie my shoes...it was gone. The knowledge was gone, and my hands were too clumsy.” Somebody said, “well get Velcro” she recalls, and “I said, no, I’m not gonna get Velcro, I’m gonna get so I can tie my shoes, cause if I don’t, I’ll never do it.” Michelle comments that it took her “ten minutes to tie my shoes. Ten minutes! But I did it, and the second one, it took me five minutes. And then every day it got quicker, and now I just do it.” Stacking colored cones is another thing my co-researcher mentions.

She describes trying to pick one up and put it on the other one, “and I couldn’t even do that.” It was these sorts of things, she explains, that “undermined my self-worth.” She remarks yet again that she felt like a two year old.

Michelle’s voice drops to a whisper as she reveals that “it was just terribly terribly frustrating,” however, she adds, “I was so determined that I was gonna do everything I could to get it back.” She reports that her

husband is just the top of the line. He was *so* supportive and he did so many things for me, I don’t know how he could stand me when I was such a mess. But anyway, he did, and it, a lot of what I got back was his, his support, and that is *so* important.

She remembers a specific instance, about a year after her stroke, in which she was trying to carry a plate of spaghetti to the table. She was using both hands, but still she dropped the plate on the floor, and “I burst into tears and I said ‘I am just such a mess I can’t even carry spaghetti to the table.’ And he said, ‘I would rather you tried, and dropped the spaghetti, than that you didn’t try, didn’t make progress.’” She says she “often thought of that, after that, when I was trying to do something. I’d think, no, go ahead, because if you do drop it, he said he’d rather have me try, and drop it, than not.” “Support from people around you is sooo important,” and she again credits her husband for encouraging and supporting her.

My co-researcher recounts a suggestion her husband made that she keep a journal. But she explains “that it’s like, if you have a terrible nightmare and you wake up and you just think, oh, I’m so glad it’s just a nightmare and somebody says, Oh quick! Write it

down, that would be so interesting! You don't *wanna* write it down, you just," "want to forget?" I offer, and she concurs, "wanna forget about it. So I didn't. Now I wish I had." Michelle indicates that those were some of the things she noticed immediately, reiterating that she "felt very vulnerable, and um, and, like I said, it took me a long time."

She reports that she was able to walk after about eight or ten days by using a hemi-walker. She digresses at this point to explain the difference between a regular walker and a hemi-walker, telling me that "you can't use a regular walker with the right side paralyzed. You can't hang on, they tried it with me and it was useless. All I did was go around in circles." We both laugh, but the moment is brief, and the mood becomes somber when she reveals that

It felt demeaning to me. I mean to me personally. I didn't care what other people saw, but to me, I just felt like, my femininity was gone, my, my uh, sense of of looking nice, and going out, feeling good about yourself, um, all my clothes were, um, I bought clothes with elastic waists so I could pull them up. Nothing with zippers, because you can't handle a zipper with one hand.

She remembers that it took her around 9 months to get control of her right hand back, "and even then it was, not good. It took me a lot longer than that to get it back." My co-researcher details some of the difficulties of dressing with one hand. In the hospital they "taught me how to get dressed all by myself, including underwear." I tell her I think "that's key" and we both laugh. She recalls, "I said, uh underwear? And the gal was really cute, the therapist, she said aren't you going to wear any?" Now we're laughing again, and she exclaims, "I said yes! But how do I get in it?" Michelle spends the next

few minutes explaining the process to me, demonstrating with her arms as she walks me through the steps. She comments that while she managed to be mostly self-sufficient, “all my good clothes hung in the closet ‘cause I couldn’t wear them anymore. They had hooks and they had, ya know, a back zipper and then any kind of a zipper I couldn’t handle.” Reflecting on that experience she declares that she “felt like a mess,” and adds that she could not do her hair because she needed two hands for her curling iron, and “this hand” she gestures towards her right, “was useless.”

Michelle tells me that it really bothered her to have “other people seeing this hand, which wanted to curl up.” She demonstrates what her right hand looked like when curled up into a fist and clenched tight to her side: “it was like this, and I thought, if I could only get it to hang down so it looked *normal*.” She thinks for a moment before continuing “because it did not look normal, and that’s a dead giveaway, when somebody has a curled arm, that they’ve had a stroke.” Michelle recounts that she “talked with other people, uh, when I’ve been on trips, and I see someone like that? And I go up and talk to ‘em, and I say you’ve had a stroke haven’t you? And they look startled and they say, yes, and I said I know why because I had a stroke too.” She indicates that once she tells them that she has also had a stroke “they just open up, ya know, and talk with you. [They see] that it’s not somebody just being, curious.”

I ask her if she thinks that it is easier to talk to other people who have had a stroke, or whether she thinks talking to other people who have had strokes is beneficial to them. She replies that “it’s beneficial for them, and maybe its beneficial to me, I’ve gone and visited a couple people in the hospital.” We talk for a couple minutes about these

visits, and she speculates that it may have also been “good for me, ya know, to say I’ve still got things that aren’t a hundred percent, but, I’ve come a long way too.” Michelle describes an occasion when an acquaintance called her shortly after her stroke, and told her that she had had a stroke about ten years previous. She recalls that they talked for over an hour, and after she got off the phone “I felt so much better because she said, well I can go out, and I can jog now, not fast, but I can jog” and her acquaintance’s stroke had been more severe than Michelle’s. She tells me that

it was great to have somebody who’d been through what she’d been through, because there aren’t people around, a lot of ‘em, who’ve had strokes, and if there are, they’re either shut up in their house cause they can’t get out, or they’re like me, where if you look at ‘em on the street you wouldn’t know they had a stroke.

My co-researcher explains that she felt that she did not have anyone to relate to, so it was really helpful when her acquaintance called and “told me some of the things that she had gone through and the fact that you survive it and you go on.” She describes it as “a real, boost” and informs me that this is what she is trying to do when she visits other stroke survivors in the hospital.

I ask her if she thinks her stroke has changed how she interacts with other people in general. She replies that this is “undoubtedly” the case, and that she is “a lot more compassionate, I think, because I’ve gone through this.” Michelle explains that “you feel pretty unfallible at one time.” She clarifies that she thought it could happen to everyone else except her, so when it did happen, it made her “feel very vulnerable, and so I relate to other people, if they have a sickness, or if they’re um, ya know, something happens.”

She says “one of the best [things] that anyone did, there was a man that went to our church, and he would say, other people would say, how are you, and I would say, I’m doing ok, ya know,” but she remembers that “he’d wait ‘til I [was] over towards the corner, cause I had to sit down. He’d come over and he’d sit down and he’d say, ‘How are you really doing?’” “Sometimes I’d just almost fall apart, I’d say no, actually, I didn’t have a very good week” and so this is what she tries to do for other people. “So like, you see, maybe I’m more compassionate” she explains, because “instead of saying, how are you, and they say fine, and I say good, if I know somebody has had a problem, or they’re really hurting or something, I wait ‘til I can talk to them, and then I, try to do that too.” She admits that she finds this “emotionally draining,” but contends that “it’s really nice to have somebody who really listens.”

I ask her if we can now discuss the second question I had prepared prior to the interview. She nods in assent, and I ask her what personal, social, and relational understandings she has come to realize in the process of living this experience. Michelle replies that she does not participate in as many social events as she did before, “simply because I don’t drive in the winter.” She used to “go to a lot more meetings and belong to committees and things,” and now she is not as “outgoing” as she used to be. “I get tired a lot easier, so I go to bed, sooner” she adds, informing me that many of these meetings happen in the evenings and it is just too late at night for her.

With regards to personal relationships she states that she thinks that she and her husband “actually got a lot closer? Because he kinda, not went his way and I went my way, but I mean we had our own interests and things, and for about two years, um, he

was my primary caretaker.” Michelle describes her husband as “very patient” and contends that it made her “appreciate him a lot more.” She recalls that when she “got better I tried to repay him in some ways,” then she laughs, “you don’t repay it.” I wonder what kinds of things she would do to “repay it” so I ask her. My co-researcher replies she does so

by being more considerate, by asking him, ya know, you want a cup of tea tonight? And he’ll say, well I can get it, and I’ll say no, let me get it. Because for so many years he had, gone out of his way to take care of me and never complained and never anything else. Maybe it’s, strengthened our relationship, not that we had a shaky one to begin with.

Michelle comments that she also became closer with her sister, “because my brother-in-law was not very, um, understanding with his stroke. He had a worse one, but he kinda took it out on my sister because he, he was frustrated.” I ask her if she thinks he was angry, and she agrees: “he was angry. Very angry.” My co-researcher tells me that her experience with stroke made her “more supportive with her,” and that it also helped her “talk with my brother-in-law because he didn’t have anybody to relate to.” We talk about her brother-in-law’s experience with stroke for several minutes, and she details several other aspects of life after stroke that she finds frustrating, such as difficulty typing, and trouble remembering numbers. She used to be excellent at math, but she does not “think it’ll get any better. And it’s frustrating to me, but other people don’t understand it, ya know.” I tell her that I am also terrible at remembering numbers, but that I was never good at it so there is no difference for me. She responds that she “really

was. I mean I loved math and I could remember things like that, but I can't anymore. Um, and I forget things. My husband will say, ya know, well don't you remember that? And I'll say, no! When was that?" She clarifies that she usually will remember it vaguely once her husband prompts her with some details. Her memory is "pretty good" but "there are times when I know there's gaps. And I don't know how to bring 'em back."

Michelle informs me that her limitations have "curtailed somewhat our doing things out of doors." She talks about how they used to go camping and hiking, but she can't anymore. "Once in awhile I'll try part way, but I just get so out of breath, and I just can't do anymore," she explains, "but, hey, that's life, ya know, it could be a lot worse." Quiet for a moment, she suggests that "maybe, maybe that's, you're more tolerant of yourself and of others, because I keep thinking of what I have come through, and where I am now, and I am so grateful. So grateful. At one time I didn't even want to live." A pained expression briefly transforms her features, and then she smiles, "I'd think, God, if you can't make me any better than this, I hope I don't wake up tomorrow. I just don't wanna, live like this. I can't do *anything*. Ya know, and now I think, look where I've come and what I can do, and be grateful for life." She explains that her gratitude helps her enjoy "the little things, the birds, or moose in the yard, or things, where before it didn't really strike me as that."

We talk for awhile about a magazine that is available to stroke survivors and their families, and what we think about it, and she begins to recapitulate some of her frustrations. She cracks a joke that makes us both laugh, and she tells me that both she and her husband have "always had a good sense of humor." She declares that to be

one of the most important things that brought me through is [that] we laughed at things that, in fact in the, um, in the uh, I.C.U, we were laughing about things, and uh, and one of the nurses came in and said, there's entirely too much laughter coming out of this room.

She says that the nurse told them that

this is supposed to be a room where everybody's upset and weeping, and she said, all I hear is all this laughter. And she was laughing too. And I thought, ya know, its, its true, she probably thinks it's so good to hear people laughing because I.C.U. is all, really a downer.

She contends that "even that made me feel better, ya know." We chat for a few minutes more, but I think that we have exhausted the topic, so I thank her for her time, and her willingness to participate.

3.4 Eleanor's Conversational Interview

I am given Eleanor's number by a friend who informs me that she has had a stroke, has heard about my study, and is interested in participating. She does not live in Fairbanks, so I conduct the interview over the phone. I call her from a quiet room in my office, and we exchange pleasantries. I feel at a disadvantage because we are not face to face and I am therefore unable to observe her nonverbal behavior. Eleanor speaks in a monotone, but seems quite pleasant, and indicates that she is very interested in my research. I read her the consent form and ask her if she has any questions. When she tells me that she "can't think of any right now," I ask her if she understands the consent

form as I have explained to her, and if she is willing to participate in my study. She says that she understands and is willing to participate.

I ask Eleanor to please describe in as much detail as possible, events or experiences since her stroke that have had an important or significant impact on how she perceives herself. “That’s an interesting question,” she comments; “I never thought about it before ... I mean there are things that I know I can’t do now. I’ve had my stroke and my left side is *slightly* affected, not a lot, but, yeah” She indicates that she does not think “there are things I can’t do. I mean there’s some things I can’t do with my left hand, but other than that, you know, I have a very supportive husband.” Eleanor clarifies that her husband “has taken me, he’s gone all the way through this thing with me.” When she had her stroke fourteen years ago “up in Fairbanks ... he was always there for me, and he took me home from the hospital and he stayed with me until we went down to, uh, Virginia Mason, in Seattle.” She explains that she was supposed to be there for a month, but that after two weeks she “had graduated from one of the programs and they couldn’t keep me there for the other one.” They sent her back to Fairbanks, “where they didn’t have the program I needed. But, a guy over at the clinic was wonderful because he did activities with me, from the program I needed.”

I ask her if she thinks that life is very different since her stroke. “Yeah, it’s a little different” she discloses, “but, you know, like, I used to be a teacher. Well now I can’t do that, but I do work with kids.” My co-researcher pauses for a moment, then indicates that she has “changed my, perception a little bit, I guess, but, ya know, now I work one on one with kids, instead of trying to handle a whole gaggle of ‘em.” I wait for her to

continue and when she does not I ask her if she perceives that her relationships with people have changed, or if the stroke has changed the way she looks at the world.

Eleanor says that she does not “think it’s changed a lot,” but adds, “you know, it may have changed a little bit, but, ya know, I just sort of go with the flow with what happens. It’s what happens” I am hoping she will elaborate, but again she does not, so I ask her what impact her stroke experience has had “on anything really.” She thinks for a minute, “well, I mean, there’s some things I can’t do, but I know the things I can’t do, you know so I just don’t even try if I can’t. And sometimes my husband will push me and sometimes he’ll go, well, ok. But he’s been supportive all the way through this thing.”

This is the second time I have heard her reference her husband’s support, so I ask her if she thinks that this support was “really important.” She agrees, “Oh yes, very important,” I prompt her for more details by asking her how he was helpful, and she clarifies that when she first had her stroke, and “they couldn’t take me down in Seattle for two weeks, that he got the wheelchair and pushed me around, and you know, he just did a lot those first couple of weeks...that I couldn’t have done for myself.” Eleanor tells me that in Seattle they were

teaching me all these things and I thought, un uh. I mean, like, they were teaching me how to make a sandwich with a board that I could push the bread up against and cut, and all this stuff, and I thought, no way! So, you know, that’s just sort of the way I approach things I guess.

I ask her to explain what she means by “no way” and she answers that “they were trying to teach me to use this stupid cutting board to build a sandwich, and I thought, I

can do it without this.” I ask her if she decided for herself what she was going to do, and what she was not going to do and she contends that she “probably decided what I *was* gonna do, not sure about what I wasn’t gonna do.” Having a difficult time getting her to elaborate, I ask Eleanor if, aside from her relationship with her husband, she thinks that interacting with people is different now. She indicates that “it’s a little different but not a lot, you know, I mean, we have lots of friends in Fairbanks and they still come over, but, my husband, he’s always been there. Cause that, you know, that’s real.”

I tell her that in my other interviews my co-researchers had talked about feeling as though they are perceived differently. I ask her if she feels like she is perceived differently now, and she replies “not really, I mean it hasn’t bothered me, I don’t think about it, so” I am having a very difficult time getting her to say more about her experience, so I ask her what she would like to talk about concerning her experience living with stroke. “Well,” she says, then is silent. I wait for a moment to see if she will continue, but she does not. I am frustrated that I cannot see her, and therefore cannot tell if she is contemplating my question, and I should give her more time, or if she does not have anything to add. I try a different approach. I ask her if she was going to explain how stroke has affected her life, or if she was going to give advice to another person who just had a stroke what she would say?

Well, probably just tell ‘em to hang in there, and I’d show ‘em, you know, if I had pictures that would be great, too, because I was, ya know, I was in a wheel chair.

I was crippled, and...I can do *anything* I want to do now, with a few exceptions,

but, you know, I'm not going to try to climb Mount Everest or anything. And I never will.

I ask her if she means that "it seems like it's bad at first, but that you'll get better"? She agrees, "yes, I mean, ya know, if you work at it you will get better. That's just like I was, I was too, and I couldn't get out of bed." She recalls that her husband said "you don't need that walker, do you? I thought, no, I don't, so, and I can walk just fine, without it. So it was just, ya know, it was the littlest things that taught me that." I ask her if she was nervous when she took those risks and she responds, "no, not really."

I ask Eleanor if her advice for other survivors would be that they should be patient and work at improving. "Yes" she agrees

and then, you know, a supportive person really helps....Cause I remember when I was laying in my place, in Seattle, and there was a lady who had a stroke, and she just, she'd given up. Ya know? And I thought, shoot lady, you're in better shape than I am. But you won't do anything; you lay in a darkened room by yourself.

I ask Eleanor if this woman was alone, and she responds that she believes that "was a lot of the problem," and she reiterates that her husband has been very supportive. I ask her if she thinks it would have gone differently if she did not have him. She tells me "oh, I'm sure. Yes, although we have good friends up, up in Fairbanks. Ya know, that we've known for 35, 40 years."

I ask her what personal, social, and relational understandings she has come to realize in the process of living this experience. She replies that she does not know "that I've come to realize anything. But I'm not sure, ya know, I don't think so." I am

surprised she feels this way because this is quite different than what I have heard from my other co-researchers, so I ask if she would consider her stroke a minor event in her life. Eleanor indicates that this is not the case; she explains that she “had to give up teaching because of it. But I had enough time that I could retire, so again.” “But it didn’t change the way you looked at the world?” I suggest, and she tells me, “not really, because I, I don’t know, my husband was so supportive, and he’d take me places, ya know, and I had a good friend up in Fairbanks who also, she’d call me up and say let’s go, and we just went all sorts of places.” My co-researcher contends that this was very helpful. I ask her if she finds getting out and being active helpful and she concurs. She tells me a story about an occasion when she went to a hot springs and it was “Easter Sunday and they weren’t serving lunch. Well, you know, I’m diabetic, I have to eat” she explains, “but fortunately, I’d taken along an emergency pack, because we’d be flying up there and everything, you know.” Eleanor clarifies that this gave her “a sense that, ya know, there’d be things like that, ya know, you have to get used to it.” I am not sure I am following her train of thought, so I ask her if she has to prepare more now and she agrees. “There are certain things, that, ya know, now I have to make sure I get my insulin and make sure I’ve got that and the other, and I didn’t have to, but now I do.”

I ask if there is anything she would like to talk about, “whatever you would consider important, basically.” Eleanor advises, “just, ya know, your attitude in coming back from it has got to be positive.” She expands, “if you’re positive and you look at the positive side of things instead of going, well, I can’t do this, I can’t do that, you go, yeah, I can do that, and uh, it just makes a big difference.” She tells me once again that her

husband has been very supportive, as well as her father-in-law and son “and that made a big difference.” She mentions visiting her father in the nursing home shortly after her stroke, and “he was wheeled out in his wheel chair and he said, Eleanor, he says, I know, why don’t you do the same thing I do, and told me about a zillion things, so, ya know, that told me that he was doing ok too.”

I ask her several questions more, but do not perceive that she has much more to say to me at this point in time. We talk for a few more minutes, and she asks me when my paper is due, telling me she would love to see a copy of it. I take down her email information and let her know I will send her a copy. I thank her for her time and insight and conclude the interview.

3.5 Lucy’s Conversational Interview

My fifth co-researcher, Lucy, contacted me after hearing about my study from an acquaintance of hers. I give her more information about the nature of my research and she agrees to meet me in my office. When Lucy arrives I introduce myself and lead her to a private interview room. In her early fifties, she looks healthy and physically fit; I cannot perceive any physical impairments or disabilities. I notice she laughs a lot, and I think it is a nervous laugh. Her voice is calm and steady, but I get the impression she may be anxious about our interview. I read her the consent form and ask her if she understands the content of the consent form as I have explained it to her; she responds that she understands and is willing to participate. I ask her if she has any questions and she says she does not.

I begin the interview by asking Lucy to describe events or experiences since her stroke that have had a significant or important impact on how she perceives herself. She admits that she was hoping I would ask her more questions than just the two I had prepared, and I perceive that she is not sure where she should begin. I tell her that she can “really start at any point you’d like.” I inform her that other co-researchers began by describing the stroke event itself, and she agrees “that’s probably the best place to start.” Lucy informs me that she was almost 52 when she suffered her stroke, “ya, so, anyway, it seemed like I was pretty young to have a stroke, so that was kind of weird in the first place.” She elaborates, “I had no risk factors, none whatsoever so ... all of the sudden, during some strenuous, night time exercise [I] had a, um, had a bad headache and [was] numb on the whole left side.” She explains that she took a nap in the hopes of feeling better, but she did not, “so I went to the hospital, anyway, so it was just totally weird.” I wonder what she felt was “weird,” so I wait expectantly, and she responds that it was because up until that point she had always been very healthy.

Lucy reflects that initially she thought “oh, I’m a stroke victim,” but that she actually does not have very many “residual problems.” She describes examining herself to see how the stroke had affected her. “Am I speaking? I’m speaking, that’s good, ya know, I can still think. So I realized it probably wasn’t too bad, and I call it strokelite” she remarks. My co-researcher thinks for a moment, then concedes that there are certain things that she notices. “I’ll notice my hand is just sitting there.” She demonstrates by laying her left hand limply on the table. When she first had her stroke she noticed that her left hand “was like a little claw.” She is not sure why this happened, but speculates

“some little synapses had to repair themselves.” Lucy informs me that it was not a very large area of her brain that was affected, but when she tells other “people [they] go, oh my god! That’s huge, but to me it was just a little area that got affected so.” She spends the next few moments detailing other things she has noticed, such as a tingling sensation on her skin, and I inform her that my Dad also has that sensation. I explain that for him it is very painful, and she replies that she occasionally feels pain but that acupuncture has helped her a great deal.

Lucy comments that “at first I didn’t want anyone to know, kinda? And that was weird.” When she does not continue I ask her why it was weird, and she responds, “‘cause it made me feel like not a healthy person, I guess. And I didn’t look like I had, ya know.” She admits that it has affected things, though, such as not being able to “stand huge sounds.” My co-researcher also mentions her parents coming to visit shortly after her stroke, “and all I wanted to do was just sleep, and be really quiet, and they, they’d want me to do things ... and it was overload, kinda like circuit overload.” She clarifies that she loves that her parents came, but she wished they would “just take care of me, but don’t talk to me, don’t expect me to talk to you, that would be the thing.”

I sense that she is talking primarily about the period of time immediately following her stroke, so I ask her if she has experienced her stroke in different phases, “like you were in different places at different times?” Lucy agrees with this, noting that “at first I didn’t want to admit, of course, it’s like a ... grieving stage, ‘cause your body changes. Although it doesn’t look like it did, it does.” I ask her if she wanted to deny the changes at first, and she answers yes, “I just didn’t wanna, I didn’t wanna *be* that person.

Whatever I was gonna be.” Then, she tells me she went through a phase in which she decided “I’ll just tell everybody, oh, I had a stroke, ya know,” but she realized that in doing so “people would come up to me, and like, treat me like a little old lady, ya know, it’s like, uh, I don’t want that either.”

Lucy conveys that when she returned to work around two months after her stroke she decided, “if people need to know, I’ll tell them, if not I’ll just keep it quiet.” She trails off into silence, so I ask her if there were any occasions where she felt like she was treated differently because she had a stroke. She contends:

There’s some people that still, ya know, and who knows? They ask me ‘How are you doing?’ And I think, it’s been three years, and I think, I’m doing fine! I have a little cold. And they’re goin’, so did you get everything back? It’s like, ooooh I know what you’re talking about! ... So it’s kinda funny, that people remembered that.

My co-researcher comments that she thinks her stroke “scared people that are my age ... I think that happened to a lot of people I knew.” I ask her if she thinks they are scared because she had been so healthy prior to her stroke, and she agrees, “yeah, yeah, yeah, they’re like, ‘ooh, that can happen to you, then, yeah, it scares them.’”

I draw Lucy’s attention back to her comment earlier about initially feeling like a “stroke victim,” and ask if her opinion has changed. “Um, sort of. I remember the toughest time I had was like the second day in the hospital, and I was just like, I didn’t know how things were gonna change in the future” referring to not knowing whether, or how much she would improve. Once she “realized there wasn’t going to be anything

worse happening” she felt “well, I survived that, ya know, now what am I here for.” She clarifies that she started to think “not that it happened for a purpose, but, just sort of looking at how I can handle things differently, ya know, or maybe it’s an opportunity to do something new.” I ask her if she means reframing it in a positive way, and she replies “yeah exactly, like how can this be a good thing, and it was a bit of a wake up call.”

Lucy remembers that initially she felt that way “really intensely,” but the feeling has faded over time. I ask Lucy to elaborate, and she explains that it is “like, what can I do now? And who can I treat nicer? And what do I need to do to make my life better?” She informs me that it was a wake up call in the sense that she realized “you could die tomorrow, and are you doing what you want to do in your life. Now. And if you die how are you going to regret things.” She explains after her stroke, she made her life “less stressful, and gradually added things back, um, that I wanted to do.”

Lucy begins to talk about her son, recalling that at the time of her stroke she had just finished menopause, and her son, who was 16 at the time, “was tough.” I ask if she means that he did not handle her stroke well, or if she found it difficult to handle him. She explains that it was both:

he was at a point where he needed to kind of break away, but, it was coming across as being *so* disrespectful, and just crazy-making for me, and I think part of it was, he was a little freaked out. He’s not talked to me about it though.

Lucy adds that her ex father-in-law “was the same way, he didn’t want to talk about it. I think he was freaked out too.” I want to know what she means by “freaked out,” so I ask her if she thought they were uncomfortable. She informs me that she did not know how

to explain to her 16 year old son that his “argumentative attitude was causing me, pain.” She laughs, “I mean, literally.” I ask her if this was because it was too much for her to process, or if she just could not handle it at that time. “I needed still some peace and quiet, I needed, like, less stress” she answers. Lucy tells me that her son ended up leaving her to live with his dad, because they had too many arguments and misunderstandings.

My co-researcher informs me that she could not explain to her son or her father-in-law “what was going on, because I’d always been, pretty tough.” I ask her if this means she feels more vulnerable since her stroke, and she thinks about this for awhile before quietly agreeing, “yeah, vulnerable is a good word. It was hard to explain to him, [my son] how things are more intense.” Her voice thickens and her eyes well with tears, “and I got more emotional too, and that really blew him away, it’s like he and his dad are like, guys, ‘we don’t do emotions.’” Lucy clarifies that she has always been “sort of emotional, but it’s more though, it’s like right there under the surface.”

I can see that she is getting emotional talking about her son, so I change the subject. I ask about the impact the stroke has had on her memory, and for the next few minutes she explains that her memory is very good. When it seems she has run out of things to say, I ask if she does different things now than she did before she had her stroke. Lucy mentions getting a dog, “and we do a lot of stuff together, ya know, skijoring, I took up skijoring, which was fun.” Laughing, she also tells me that she had to give up hockey, “which I loved!” and that she has cut back to working only four days a week.

I ask if she thinks any of the things she just mentioned impact how she perceives herself, or how she believes others perceive her. She laughs, then pauses for awhile, then replies that she does not know “how they perceive me. I think they think I’m pretty active, the people that I do know.” Lucy appears at a loss, so I prompt her, “and as far as you see yourself?” She explains that she keeps busy and that helps her feel more useful and active. She has joined Big Sisters, which helped her “with losing my kid,” although she adds, “now, we’re like, pretty tight again,” and conveys that she is not sure if her difficulties with her son had anything to do with her stroke.

Another long pause ensues, so I ask her if she would like to address my second question, or if she has more to say about stroke’s impact on her self perception. Lucy informs me that “the big thing” was realizing that she should not talk about it, “because I didn’t like how they, might perceive me, I feel pretty whole, most of the time.” She also tells me that she is unsure if “things in her personality” have actually changed, or if she is “just noticing them more” now. As an example is that if she gets upset at work, she wonders “would I have got that upset before? Or would it have affected my head as bad as it does now?”

She informs me that she is ready to address my second question, so I ask what personal, social, and relational understandings she has come to realize in the process of living her stroke experience. Lucy remarks that she had two friends with whom she was close to at the time of her stroke, and had been friends with for the previous twenty years, “and I had my stroke about the anniversary of one of ‘em [a third friend] dying, so I had the feeling ... I thought the other two, especially one, kinda resented the fact that I’d

gotten sick.” She recalls that one of these friends, who had taken care of their other friend before she died, told her ““I pretty much have been through all that, and I’m not going to do it again.”” My co-researcher clarifies that she felt that she “kinda needed” this friend “but after awhile, I processed that and processed that, and I didn’t initiate any contact with her for a long time. In fact a year.” She laughs nervously. I ask if this was because she was angry or resentful, and she agrees she was angry, but also that she felt “she knows what’s going on, if she wants to have contact with me, I guess I’ll let her decide when she’s able to do that.” She informs me that they have done “maybe one thing in three years.”

Lucy reports that her other friend’s actions are “and this is why I’ve stopped telling people I’ve had a stroke. I kept hearing that this other friend was assuming things about me, like I wasn’t getting the treatment I was supposed to.” Lucy resented this because she “never figured out what her problem is with what I was doing,” and her friend would not call her up directly and ask her about her treatment. These friends were around her age, and she thinks “it freaked them out to a major degree, and I still haven’t had much contact with either one of those people.” Lucy adds that she is “fine without them. I made a whole new set of friends, basically, which was kinda weird but, it was just good timing.” She admits that she does still think about those two friends, but that she is “real hesitant to put herself out there anymore for them.” I ask her if this is a “trust issue,” and she replies, “yeah, I mean if I tell them anything I don’t want it to end up back around to someone else, ya know, if they’re wondering about me, they can call,

find out how I'm doing, even three years later." She talks a long time about these two friends, and I perceive they have hurt her a great deal by not being "there for her."

I ask if it was really difficult to lose that support, and she answers "kind of," but that she wasn't sure what they could do for her. She does, however, recall asking one of her neighbors to take her to the Jacuzzi, "and it happened one time and then she never called me again! So I was like, ok, well I have to figure out another way to do it." Lucy asserts that this "changed how I look at ... when other people are sick ... you may not know what I can do for you, but I'll keep trying, and I'll suggest things, ya know." She adds that "being sick helped me realize that I can ask other people for help, and a lot of them are just willing to do it, so that was cool. And I did ask for help, more than I wanted to," and laughs again.

She brings the conversation back to her son, reiterating some of the difficulties she had in her relationship with him, but contending that they have a good relationship now: "we're back to where he thinks I'm just a silly old mom, and out of it, and not very cool, which is normal." We both laugh. I ask Lucy if she would give advice to other stroke survivors, what she would say. She replies, "just to know that things'll get better" and "to take it, just, really easy at first, just call in all your support systems, call in all the people that you've helped, just kinda let things go." She elaborates that stroke survivors should let other people take care of things, "ya know, not trying to be as in control, and things'll change, and not necessarily for the worse." Since she has mentioned that it is not necessarily worse, I ask her if she can think of any positive outcomes of her stroke.

Lucy thinks for a long while, then tells me that she got in touch with a lot of friends she had not talked to in a long time, and that she now understands

older people that I know, and not necessarily [those who] have had strokes, but, ya know, are slower and more deliberate. I think in the past I would probably think, ah well, there's a old person, ya know; I think about them better, ya know, they have all the information they used to have, they're just slower at processing it.

We talk for several more minutes, as she tells me about some of the difficulties she is facing at work. I do not perceive any new themes emerging, so I thank her for participating in my study, and end our interview.

Chapter 4

Human Science Research Analysis

In my final chapter I am obliged to offer my interpretation of the stroke experience based in my personal understanding of my father's stroke experience, my study of the stroke literature, and my exploration of the meanings co-constructed in the conversational interviews with my co-researchers. I have immersed myself in the recorded interviews, and interview transcripts, looking for overlapping patterns across the co-researcher's experiences that might suggest commonalities in understanding. During this analytic step, I carefully studied the transcribed narrative for emergent words, phrases, and relationships that expressed common experiences of the co-researchers. I developed these emergent themes to represent the co-researchers' collective experience of the research phenomenon.

4.1. Theme One: I'm A Survivor

*Cheerfully surveying
The landscape of my disability
It's east by best
Attitude and longitude*

*Precipitously conveying
A tone of quiet optimism
Not denial
This is survival.*

~Ruth Harrigan

In each of my interviews, co-researchers presented themselves as strong, capable, and optimistic women who have persevered and overcome. They eschew self pity in favor of accepting that certain deficits incurred by their stroke are beyond their control

and work continuously to improve in the areas they can. They communicate acceptance of their new circumstances in a variety of ways. Prudence indicates that her stroke is a “part of life ... you don’t go through this routine that people go through where [they ask] why did it happen lord, why me, all that. Things. Just. Happen.” Similarly, when Michelle discusses no longer being able to go hiking or camping with her husband, activities she once enjoyed, she tells me “but, hey, that’s life, ya know, it could be a lot worse.” Eleanor voices her acceptance in her assertion that whereas her life “may have changed a little bit” she “just sort of go[es] with the flow with what happens. It’s what happens.”

Folden (1994) asserts that many stroke survivors have the ability to accept that they will never be able to return to their pre-stroke life, but are likely to set personal goals that help them undertake some of their pre-stroke activities. They continue to be active interpreters of their experience, learning to adjust, vary, revise, and amend so they may live their lives as best they can manage. All my co-researchers present themselves as optimists, addressing the importance of maintaining a positive outlook after the occurrence of a stroke. Julia suggests that “you sort of have to get that attitude afterwards to really be successful too, ya know?” elaborating that after she woke up from her three day coma she felt “like you’re maybe not going to live ... but then I feel like I made a miraculous comeback, and that there is always hope too.” Eleanor explains that she is optimistic because “if you’re positive and you look at the positive side of things instead of going, well, I can’t do this, I can’t do that, you go, yeah, I can do that ... it just makes a big difference.” Michelle stresses the importance of laughter in her life,

articulating that “one of the most important things that brought me through is [that] we laughed at things,” a sentiment Prudence validates when she describes her 911 experience as “hysterical.” My final co-researcher, Lucy, recalls checking out the damage of her stroke and realizing she could still “speak” and “think” and “so I realized it probably wasn’t too bad, and I call it strockelite.” This minimization reflects an optimism that is characteristic of all my co-researcher’s experiences.

The manner in which my co-researchers articulate both advice they have received from other stroke survivors and advice they would offer given the opportunity also reflects this optimistic approach. Michelle explains that she felt she did not have anyone to relate to, so it was really helpful when her acquaintance called and “told me some of the things that she had gone through and the fact that you survive it and you go on.” She describes it as “a real boost” and informs me that this is what she is trying to do when she visits other stroke survivors in the hospital. Eleanor tells me she would advise other stroke survivors “to hang in there, and I’d show ‘em, you know, if I had pictures that would be great, too, because I was, ya know, I was in a wheel chair. I was crippled, and, I can do *anything* I want to do now.” Lucy stresses that it is important “just to know that things’ll get better,” adding that “things’ll change, and not necessarily for the worse.”

My co-researchers describe seeking “a state of health that represents their best effort within the specific challenges of their condition” (White & Johnstone, 2000, p. 142). Most self-identify as hard workers. They stress the importance of perseverance after a stroke. Julia articulates this well; “when I do anything, it’s like, ok, can I go one step further this time? Can I walk, uh, 20 steps further on this trip? [I am] always like ok,

you've gotta improve, and I think that I'm real careful now to maximize everything."

Michelle echoes this sentiment when she tells me that she "was so determined that I was gonna do everything I could to get it back," and Prudence reiterates that "Anything I could do to get around, I do it."

While Pearson (2004) contends that "much of the literature conceptualized people with stroke as passive in response to their situation rather than active and imaginative" (p. 414), another commonality among my co-researchers was a dismissal of the limitations imposed upon them by their health care providers. They present themselves, instead, as autonomous decision makers in their own recovery. Prudence recollects flying to Atlanta against the wishes of her providers, "I made all the arrangements and then I told the therapy folk- I'm going to Atlanta anyway." She tells me that after her doctor told her that she would never be able to walk or teach again, "I decided, lady, you don't know me. [She] made a general, generalization, without any knowledge. I *have* taught, and walked." Eleanor also mentions disregarding the advice of health care professionals; "they were trying to teach me to use this stupid cutting board to build a sandwich, And I thought, I can do it without this." In my interview with Michelle, she recalls ignoring advice that she should get shoes with Velcro; "I said, no, I'm not gonna get Velcro, I'm gonna get so I can tie my shoes, cause if I don't, I'll never do it."

4.2. Theme Two: Talk To Me Normal!

*Passing me by you just don't see,
The person but only the wheelchair, not me,
I may not be able to walk,
But give me a chance and I will surely talk of many things,
That life has to offer and to me brings,
You see,*

*I see from a different point of view,
I have to look up and what I see is you
and because of these wheels that carry me along,
I have much more time to consider what's going on.*

~Michele Sutphin

One of the most prevalent themes that emerged from my research was the impression expressed by co-researchers that they are treated differently since their stroke. Feelings of being ignored or being treated like a child, or an old lady, are expressed in many of my co-researcher accounts. Whereas none of my co-researchers would agree that they are incapable, incompetent, or invisible, the way they are treated by others makes them feel as though they are inconsequential. In my conversation with Prudence, she explains that her experience immediately following her stroke was “not very pleasant in general because, they basically treat you like a five year old, if not younger.” She recollects offering the same advice to a technician as her husband later offered, “and she did listen to him. But she obviously, at that time, wasn’t listening to me.” Prudence juxtaposes this against an instance where she was taken seriously by hospital staff: “They decided maybe there was more up here,” she points to her head, “than they thought” implying that before that moment she had been treated as though incompetent.

Julia’s experience echoes that of Prudence when she indicates that she thinks people ignore her, “when in the wheelchair especially, but even now.” She describes going to an appointment and everyone talking to her husband instead of her. She comments “they wouldn’t even look at me and I’m like, ok, wait a minute, I’m here. I can answer that!” To further illustrate this point she describes her nutritionist approaching her husband, and telling him “would you give this report to her, and tell her

to do this” to which her husband replied “no, you need to tell her.” Julia explains that it is “very, very, ah just maddening to not have people talk to you, and I can talk, and I can answer questions, so I’m wondering why, especially if you’re in a wheelchair, do people not talk to you?” She tells me that when people “see someone in a wheelchair, or with any disability, that doesn’t mean you should not communicate with them,” and she further advises, “don’t treat them like they are disabled, be totally normal.” Julia discloses that she “just told one of my kids the other day, if I have another stroke, you come and you talk to me as normal.”

“Normality” is something for which many of my co-researchers strive, reflecting their desire to be treated as they had been before they had a stroke. They do not identify with the sickly, broken, incompetent role some people ascribe them. Stroke survivors have reported that how other people reacted to them was “important in the preservation of self-esteem and in the formation of social identity” (Murray & Harrison, 2004, p. 812). This may be why two of my co-researchers report using strategies that minimize the visibility of their stroke. Michelle tells me that it really bothered her to have “other people seeing this hand, which wanted to curl up ... I thought, if I could only get it to hang down so it looked *normal*.” She thinks for a moment before continuing “because it did not look normal, and that’s a dead giveaway, when somebody has a curled arm, that they’ve had a stroke.” Similarly, Lucy describes her discomfort with others knowing that she has had a stroke, “at first I didn’t want anyone to know, kinda? And that was weird ... ‘cause it made me feel like not a healthy person, I guess.” At another point in our discussion she elaborates on why she does not like to disclose that she has had a stroke;

explaining that when she did tell “people would come up to me, and like, treat me like a little old lady, ya know, it’s like, uh, I don’t want that either.”

4.3. Theme Three: *I Am A Better Person Now*

*Love that lies deep inside of me
Come forth in all thy unity
Let me be thy gaze
Let me teach thy ways
That I a better person may be*

~Author Unknown

An emergent theme that mirrors my own experience with my father is the assertion that stroke makes you a better person. My co-researchers explain that after one has a stroke, the uncertainty of their condition triggers a reappraisal of how they have been conducting their lives. When one suffers a stroke, one’s sense of continuity with one’s past is undermined and one’s future becomes unpredictable (Ellis-Hill & Horn, 2000). Stroke survivors worry that their condition may not improve, that they may have a second stroke, or that they may die. Julia explains that her stroke “sort of put the brake, ya know, when you’re laying there after the stroke, you don’t know if you may have another one, and live, or not.” She indicates that it has made her more careful, and “that’s a good part of it.” She remarks that the stroke has made her “have a real, um, realization of how important relationships are,” adding that “in a way I’m a better person now, through this.” She values who she has become since her stroke so much that she does not “know that I would even go back to the way I was before.” Because she is “sure I did this too, before the stroke,” but she has “a lot of insight now, and a lot of empathy, that I didn’t have before.”

Michelle contends that she is “a lot more compassionate, I think, because I’ve gone through this.” She explains that she had always thought strokes happen to other people, so when she had one it made her “feel very vulnerable, and so I relate to other people, if they have a sickness, or if they’re um, ya know, something happens.” She suggests that “you’re more tolerant of yourself and of others, because I keep thinking of what I have come through, and where I am now, and I am so grateful. So grateful. At one time I didn’t even want to live ... and now I think, look where I’ve come and what I can do, and be grateful for life.” She explains that her gratitude helps her enjoy “the little things, the birds, or moose in the yard, or things, where before it didn’t really strike me as that.”

Lucy remembers that “the toughest time I had was like the second day in the hospital, and I was just like, I didn’t know how things were gonna change in the future,” referring to not knowing whether, or how much she would improve. She explains that this got her “sort of looking at how I can handle things differently, ya know, or maybe it’s an opportunity to do something new ... like how can this be a good thing, and it was a bit of a wake up call.” She explains that she started asking herself, “what can I do now? And who can I treat nicer? And what do I need to do to make my life better?” She adds that it changed how she perceives other people, particularly older people she knows: “I think in the past I would probably think, ah well, there’s a old person ... I think about them better, ya know, they have all the information they used to have, they’re just slower at processing it.”

4.4. Theme Four: I Need Support

*And so we danced and felt complete,
A couple not quite deft;
For though he danced with two left feet,
I danced with one foot left.*

~D. Elizabeth Robinson

Social support, or “the experience or information that one is loved and cared for, valued and esteemed, and able to count on others should the need arise” (Pound et al., 1999, p. 126), plays a critical role in the recovery process. Egbert et.al. (2006) assert that “communication processes are the medium through which support is provided to individuals as they cope with everyday stresses and health crisis” (p. 268). Albrecht and Goldsmith (2003) further validate the importance of supportive communication for recovery, contending that “supportive communication plays a complicated, direct, and mediating role in the course and experience of health and illness” (p. 277).

Each of my co-researchers talked at length about their support networks, and the pivotal role support plays in the recovery process. Lucy explains that she would advise other stroke survivors to “call in all your support systems, call in all the people that you’ve helped.” Julia tells me, “I want a lot of human contact.” She recalls that when she was in rehab, that was “sooo important to everybody. I don’t know why, but it’s real important to have lots of input, lots of contact.” She adds, “what maybe would’ve been just a minor, hi and goodbye kind of relationship [before the stroke] is now more than that, it’s like, lots of contact on the phone with people. And I, for me that’s really important.” She comments that her family has been great, and that it “would be really hard without a supportive family. Because I live in my own home, ya know, somebody’s

transporting me if I'm not driving, and so... it's been, it's been easy because I have a really supportive family." She indicates that "without that, it might be a whole different story. It would be." In my interview with Michelle, the importance of support was also highlighted. She contends that, "support from people around you is sooo important."

Banks and Pearson (2004) observe that "when a family member experiences illness, other family members have to adapt to a change in roles, structures and ways of relating" (p. 426). They reinforce this notion of interconnectedness when they draw attention to the difficulty of sorting out the caring situation "from the relationship in which it is experienced and the need to recognize that the individual needs of carers and cared for are often inextricably linked, based on the shared history and emotions pertaining to their relationship" (p. 415). Research also indicates that married stroke survivors who have large and supportive social networks have an increased chance of successfully returning to an independent living situation (Egbert et al., 2006).

Four of my five co-researchers report having extremely supportive husbands who were pivotal to their post-stroke success. Prudence spends a great deal of time detailing all her husband has done to accommodate her post-stroke capabilities, such as making their home accessible for her, preparing meals, and cleaning their home. She also indicates that "he takes me everywhere right now," and that he is "perfectly happy to take me anywhere I want to go, like bringing me here." Eleanor conveys that her husband "has taken me, he's gone all the way through this thing with me ... he was always there for me." She reiterates that her husband has "always been there. 'Cause that, you know, that's real." Michelle also reports that her "husband is just the top of the line," adding

that “he was *so* supportive and he did so many things for me, I don’t know how he could stand me when I was such a mess. But anyway, he did.”

Some of my co-researchers also indicated that their husbands were an important source of motivation for recovery. Eleanor contends that “sometimes my husband will push me and sometimes he’ll go, well, ok.” She recalls an occasion shortly after her stroke when her husband said “you don’t need that walker, do you? I thought, no, I don’t, so, and I can walk just fine, without it.” Michelle also mentions her husband as a powerful motivational source. She discusses a memory of crying after dropping spaghetti on the floor and her husband telling her, ‘I would rather you tried, and dropped the spaghetti, than that you didn’t try, didn’t make progress.’” Michelle informs me that she “often thought of that, after that, when I was trying to do something. I’d think, no, go ahead, because if you do drop it, he said he’d rather have me try, and drop it than not.”

Although my co-researchers express much love and gratitude for the support of their husbands, some of them also mentioned disliking that they had become so dependent on them. Julia thinks her husband has dealt with her stroke better than she has, explaining that her husband “does the laundry now, he does the things, so many, that I used to do. And he’s ok, but again it’s, I would like to be that person.” Similarly, Prudence describes her husband as an amazing caregiver, but admits that she did not like that he had to do so much work for her when she returned home, contending that this was “because I’d been too independent before. We were both professionals, and he did his thing and I did my thing. And I couldn’t drive, or anything, so anytime I wanted to go anywhere I had to get him.” Michelle, while not communicating a dislike for her

newfound dependence, indicates that before her stroke “he kinda, not went his way and I went my way, but I mean we had our own interests and things, and for about two years, um, he was my primary caretaker.”

Another aspect of social support that some of my co-researchers stressed was important to recovery is “getting out.” Community re-integration, defined by Egbert et al. (2006) as “re-establishing, to the degree possible, previously existing roles and relationships, creating substitute new ones, and assisting people in making these changes” (p. 46), is often pivotal to the stroke survivor’s perceptions of successful recovery. The social context of recovery is important because most stroke survivors focus on recovery that will “enable participation in the social world through adaptation and the development of coping skills, rather than improvement in discrete physical function alone” (Burton, 2000, p. 307). Prudence asserts that she “gets out quite a lot” and spends a great deal of time relaying ways in which she has remained active in the community. Julia explains that it is important “to get out and about,” because it helps her “to be part of the community again.” She gives the example of her son calling her and inviting her to watch the basketball games; “it’s like, come on to the game mom, and that is, it is really good to get out, and still feel like you are not, um, a disabled person that just has to stay shut away. I think that is just not healthy at all.”

Friends and family also play a key role in my co-researchers’ interpretations of their stroke experience. Prudence indicates that she has a very good support group, asserting that “the people who were my best friends, women, that is, before the stroke are still my best friends after it. They come visit, they take me places, and we do all kinds of

things.” Julia contends that her friends actually “worked harder at being friends. I mean, they really do still put in the time to make sure, you know a birthday or something is a big deal.” And while she can no longer do a lot of the projects they used to work on together, like making scrap books, she remarks that “we spend more time visiting, so, um, I would say definitely the friendship bonds are thicker now.” Eleanor also mentions “a good friend up in Fairbanks who also, she’d call me up and say let’s go, and we just went all sorts of places.” Julia asserts her family has been very helpful; “they really hover around me and help. They’re like ‘do you need this Mom, do you need that?’” She adds that “it would be really hard without a supportive family.”

In addition to these lengthy discussions of how important social support has been in their recovery, most of my co-researchers also told cautionary tales about the danger of social isolation after a stroke. Prudence talks about an acquaintance who had a stroke long before she did, who suffered many different cognitive impairments, and who almost committed suicide before he was stopped by friends. She explains that they took him out to the horse stables, put him on a horse, led him around, and told him that they would be doing the same the following day. His friends were able to get him interested in horses and “then he could just go out there by himself because there were always people there. And he rode, ya know, groomed horses did all sorts of things, he got interested in something, so uh, it saved his life.”

Michelle speaks about her brother-in-law not being “very, um, understanding with his stroke. He had a worse one, but he kinda took it out on my sister because he, he was frustrated.” She conveys that she can now relate to him, but before “he didn’t have

anybody to relate to” and so has spent a lot of time in seclusion. Eleanor remembers when she was still an in-patient after her stroke that “there was a lady who had a stroke, and she just, she’d given up. Ya know? And I thought, shoot lady, you’re in better shape than I am. But you won’t do anything; you lay in a darkened room by yourself.” When I ask her if this woman was alone, Eleanor responds that she believes that “was a lot of the problem.” Julia also comments that she thinks it is very important to have a lot of contact with people after a stroke, explaining that “sitting for long periods of time alone with no, that is not good, that is just not good at all.”

Among my five co-researchers Lucy is the only one who does not report having a wonderful support system. She spends much of our interview discussing the relational difficulties that came about after she suffered a stroke. She mentions that at the time of her stroke she was raising a 16 year old son, who ended up leaving her to live with his dad because they had too many arguments and misunderstandings. Lucy informs me that she could not explain to her son or her father-in-law “what was going on, because I’d always been, pretty tough.” She relays that “it was hard to explain to him, [my son] how things are more intense ... and I got more emotional, too, and that really blew him away, it’s like he and his dad are like, guys, ‘we don’t do emotions.’” Lucy adds that her ex father-in-law “was the same way, he didn’t want to talk about it. I think he was freaked out too.” She also remarks that she had two women with whom she had been friends for the previous twenty years, “and I had my stroke about the anniversary of one of ‘em [a third friend] dying, so I had the feeling ... I thought the other two, especially one, kinda resented the fact that I’d gotten sick.” She recalls one of these friends telling her, “I

pretty much have been through all that, and I'm not going to do it again.” Lucy felt that she “kinda needed” this friend “but after awhile, I processed that and processed that, and I didn't initiate any contact with her for a long time. In fact a year.” She informs me that they have done “maybe one thing in three years.” These friends were around her age, and she thinks “it freaked them out to a major degree, and I still haven't had much contact with either one of those people.”

4.5 Conclusions and Prospects for Further Inquiry

My interpretation of my co-researcher's experiences both reinforces what has been said by previous researchers of the stroke phenomenon and provides insight into how survivors of stroke self-identify. My first three themes speak to my co-researchers rejection of a victim label, which in turn functions as a rejection of the assumptions embedded in the traditional medical model about the nature of health and well-being. Newsome and Schultz (1998) contend that in “the traditional medical model, health and well-being are often defined by professionals as what an individual's life was pre-stroke. Any disability is defined as a deficit; pre-stroke life is superior; post-stroke life is seen as devastating and substandard” (p. 177). In contrast, my co-researchers favor interpretations of their stroke experience that allow the most potential for personal growth and happiness. My co-researchers express the importance of hearing and telling stroke survivor stories that provide hope and inspiration. In identifying as survivors they are highlighting inner strengths and abilities, and downplaying physical weaknesses and limitations. Their stories are renewal stories that view the experience of stroke as a personal call to reevaluate one's life. These survivors have been led to reassess

significance in their lives and have recognized the need for different priorities. Their attention has been brought by their strokes to a focus on the limits to their time of life. The recognition of the fragility and shortness of their potential lives has engendered a jettison of the trivial and an energetic embracing of those experiences and people they have identified as important in their lives.

Positive framing seems to be very important in the development of a successful post-stroke identity, yet it has received little attention in the literature. McPherson et al. (2004) criticize the “lack of consultation about what constitutes meaningful health outcomes” (p. 988), suggesting that the “lived experience of disability” and “insider perspectives” are often outside the purview of clinicians. In a similar vein, Anderson and Marlett (2004) highlight the discrepancy between those outcomes considered desirable within the medical community, and those outcomes considered valuable by the stroke survivors themselves. They posit that whereas professionals communicate about treatment of the patient’s disease, bodily impairment, and problems of reduced functioning, stroke survivors portray themselves as people with a life in society that they wish to retain.

Lorber (1997) offers an alternative framework better suited for engendering meaningful health outcomes called the social construction of illness. She asserts that although illness is located in the body, as a social experience it exceeds physiology and involves all aspects of social life, such as “interlocking social roles, power and conflict, social statuses, networks of family and friends, bureaucracies and organizations, social control, ideas of moral worth, aspects of work and occupations, definitions of reality, and

the production of knowledge” (p. 4). Whereas feeling ill or healthy is a personal experience, our understandings of what health and illness mean are drawn from our experience of the relevant culture (Miles, 1991).

The second theme that emerged from my research, “talk to me normal,” reinforces Lorber’s (1997) assertion that what people actually experience as illness is synonymous to any disturbance in their social lives which prevents them from pursuing their usual, everyday activities; which may or may not be the result of actual physiological dysfunction. One of the biggest challenges reported by my co-researchers was not their physiological limitations, but undesired changes in their interpersonal communication with others. In rejecting a victim identity in favor of a survivor identity my co-researchers are rejecting an identity of illness as well. Yet even though they reject an identity of illness, they report that such an identity is nevertheless often ascribed to them. Illness, particularly stroke, is often associated with weakness, fragility, and senility within American culture. As such, those who have limited personal experience with what it means to suffer a stroke often perceive stroke survivors as incompetent or irrelevant. My co-researchers describe this as “frustrating” and “maddening” because this ascription clashes with how they perceive themselves. Stroke is unique in that very little is known about how the individual brain is impacted and what residual deficits the particular survivor will suffer. Individuals may suffer severe physical set backs without suffering cognitive limitations, yet they may still be treated as though they are no longer mentally capable.

The third theme that emerged in my research, “I’m a better person now,” is not one that I have seen reflected in the literature, but is true to my own experience and the experiences of my co-researchers. Burton (2000) suggests that critical to stroke survivor adaptation is the transformation of fundamental assumptions they have developed over their life’s course about who they are, and where and how they fit into their social worlds. Whereas in contemporary, secular, Western culture, suffering a stroke is assumed to be wholly adverse and devoid of value, many of my co-researchers report that the compassion of loved ones after a stroke that left them vulnerable and dependent and led them to appreciate interpersonal relationships more. In facing their own mortality, my co-researchers have reported a shift in perspective which has implications for how they communicate with others, choose to invest their time and energy, and enact relationships. They self-identify as having greater insight, empathy, and patience in the wake of their stroke.

My fourth and final emergent theme highlights the critical role social support plays in the construction of an empowered post-stroke identity. My interpretation complements the findings of many previous researchers of the stroke experience. The importance of social support was the most consistently articulated theme across co-researchers. In our interviews, my co-researchers discuss the types of support they have found most helpful in their recovery and the type of communication they desire. Whether from healthcare professionals or the general public, my co-researchers desire to be treated as competent, active decision makers and interpreters of their own stroke experience; not ignored or talked to as though a child; in short, to be treated “normal.” From friends and

family they express their desire to be treated with patience and compassion. My co-researchers report an increased appreciation for mundane conversation, as well as a desire to remain socially active. They tell stories of friends and family taking them places, and coming up with alternative activities in instances when physical limitations would preclude their participation. My co-researchers also discuss turning to other survivors for hope, by way of stories of improvement and recovery. They look to one another for advice, coping strategies, and emotional support.

New insight and understanding can be achieved by studying how people frame their life experiences in everyday conversation. Anderson and Marlett (2004) have emphasized the need for more in-depth analysis of post-stroke communication, yet much of the literature currently available concerning the consequences of stroke is restricted to examinations of the physical and functional deficits incurred, and the ways in which stroke sufferers can be rehabilitated most successfully. They suggest that whereas “communication is perhaps the most essential ingredient in effective health care and could be one of the most powerful tools in stroke recovery; informal interpersonal communication has received very little attention” (p. 55).

All meaning is created, recreated, and re-imagined in communicative interaction; who we are and how we interpret life events is developed in communication with others. Understanding the fundamental role communication plays in the meaning-making process leads us away from approaches to understanding or conceptualizing illness strictly in terms of physiological symptoms alone. Insight into how patients actually experience illness is vital to the development of appropriate strategies to aid recovery.

Whereas one's interpretation of their health is critical to their sense of being, their notion of personal identity, and their understanding of reality, people are rarely conscious of or able to articulate their meanings for health (Shulka, 2001). Identity is at the core of how one understands health and acts on those understandings, and "because identity is itself the product of communicative interactions, communication must be at the very core of what it means to be healthy" (Lambert et al., 1997, p. 36). Survivor perceptions of health, illness, sickness, and disease are connected to their sense of what is normal and what is not, which roles they should enact, and what the changes they experience mean.

Future research should examine the powerful role positive framing plays in stroke recovery, and the means for its utilization to maximize post-stroke success should be investigated. Moreover, whereas my co-researchers present themselves as survivors, they report feeling silenced and marginalized by others who refuse to acknowledge this self-construction. Further research should be conducted which investigates the unique challenges stroke survivors face in negotiating disparities between self perception and how they are identified by others. Additionally, the impact and implications of perceiving oneself to be a better person after stroke has not been given due attention within the literature, and merits further consideration. Positive self-image appears to be critical in the construction of an empowered post-stroke identity, yet little time has been spent examining ways in which such empowerment can be fostered both in therapy and during the reintegration process. Lastly, as social support appears to have a profound impact on whether stroke survivors thrive or deteriorate, an essential element of post-stroke rehabilitation should be the promotion of social interaction and human connection.

When I initially began this research I knew very little about the stroke experience. I am a healthy, young woman who has never experienced a major medical crisis, nor spent a significant amount of time with anyone who must deal with health concerns on a daily basis. I was living independently of my family when my Dad had his stroke, so I have not experienced the day to day details of the experience as my Mom has. As such, I had few preconceptions about what my co-researchers would say. What I learned in this process not only has implications for future research and medical practice, but also for how I understand and interact with my Dad. This study has given me invaluable insight into life after stroke that influences both how I interpret my father's experience and demonstrate support. It is imperative that we seek out and listen to the voices of those who have experienced health crises. Through their stories we can find understanding, and with understanding an improved capacity to facilitate health outcomes they find most meaningful.

References

- Albrecht, T. L., & Goldsmith, D. J., (2003). Social support, social networks, and health. In Thompson, T. L., Dorsey, A. M., Miller, K. L., & Parrott, R. (Eds.), *Handbook of health communication*. (pp. 263-284). Mahway, NJ: Erlbaum.
- Anderson, S., & Marlett, N.J. (2004). The language of recovery: How effective communication of information is crucial to restructuring post-stroke life. *Topics In Stroke Rehabilitation, 11*, 55-67.
- Anderson, S., & Marlett, N.J. (2004). Communication in stroke: The overlooked rehabilitation tool. *Age and Ageing, 33*, 440-443.
- Banks, P., & Pearson, C. (2004). Parallel lives: Younger stroke survivors and their partners coping with crisis. *Sexual and Relationship Therapy, 19*, 1468-1479.
- Bleakley, A. (2005). Stories as data, data as stories: Making sense of narrative inquiry in clinical education. *Medical Education, 39*, 534-540.
- Burton, C.R. (2000). Living with stroke: A phenomenological study. *Journal of Advanced Nursing, 32*, 301-309.
- Cannuscio, C.C., Jones, C., Kawachi, I., Colditz, G.A., Berkman, L., & Rimm, E. (2002). Reverberations of family illness: A longitudinal assessment of informal caregiving and mental health status in the Nurses' Health Study. *American Journal of Public Health, 92*, 1305-1311.
- Carter, R. E., & Carter, C. A. (1994). Marital adjustment and effects of illness in married pairs with one or both spouses chronically ill. *The American Journal of Family Therapy, 22*, 315-236.

- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Thousand Oaks, CA: Sage.
- Deetz, S. (1982). Hermeneutics and research in interpersonal communication. In J. J. Pilotta (Ed.), *Interpersonal communication: Essays in phenomenology and hermeneutics*. pp. 1-13. Washington, DC: Center for Advanced Research in Phenomenology & University Press of America.
- Denzin, N. K., & Lincoln, Y. S. (2000). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research (2nd ed.)*, (pp. 1-28). Thousand Oaks, CA: Sage.
- DesRosier, M.B., Catanzaro, M., & Piller, J. C. (1992). Living with chronic illness: Social support and the well spouse perspective. *Rehabilitation Nursing, 17*, 87-91.
- Egbert, N., Koch, L., Coeling, H., & Ayers, D. (2006). The role of social support in the family and community integration of right-hemisphere stroke survivors. *Health Communication, 20*, 44-55.
- Ellis-Hill C.S., & Horn S. (2000). Change in identity and self-concept: A new theoretical approach to recovery following a stroke. *Clinical Rehabilitation, 14*, 279-287.
- Faircloth, C., Boylstein, C., Rittman, M., & Gubrium, J.F. (2005). Constructing the stroke: Narratives of stroke survivors. *Qualitative Health Research, 15*(7), 928-941.

- Folden, S.L. (1994). Managing the effects of a stroke: The first months. *Rehabilitation Nursing Research*, 3, 79-85.
- Gergen, K. J. (1994). *Realities and relationships: Soundings in social construction*. Cambridge, MA: Harvard Press.
- Gergen, M. (2001). *Feminist reconstructions in psychology: Narrative, gender, and performance*. Thousand Oaks, CA: Sage.
- Giacino, J.T., & Cicerone, K.M. (1998). Increasing quality of life and awareness of deficits in persons with traumatic brain injury: A pilot study. *The Journal of Rehabilitation*, 618-635.
- Glass, T.A., & Maddox, G.L.(1992). The quality and quantity of social support: Stroke recovery as psychosocial transition. *Social Science Medicine*, 34, 1249–1261.
- Gordan, P.A., & Perrone, K.M. (2004). When spouses become caregivers: Counseling implications for younger couples. *Journal of Rehabilitation*, 70, 27-32.
- Harre, R. (1995). Agentive discourse. In R. Harre & P.S. Sterns (Eds.), *Discourse Psychology in Practice*. Thousand Oaks, CA: Sage.
- Hochstenbach, J., Donders, R., Mulder, T., Van Limbeek, J., & Schoonderwaldt, H.(1996). Long-term outcome after stroke: A disability orientated approach. *International Journal of Rehabilitation Research*, 19, 189–200.
- Kaufman S.R., & Becker G.(1991). Content and boundaries of medicine in long term care: Physicians talk about stroke. *Gerontologist*, 31, 238–245.

- Kelly, M.P., & Millward, L.M. (2004). Identity and illness. *Identity and Health*, 11, 1-18.
- Kirkevold, M. (2002). The unfolding illness trajectory of stroke. *Disability & Rehabilitation*, 24, 887-898.
- Kurz, J. M., & Cavanaugh, J. C. (2001). A qualitative study of stress and coping strategies used by well spouses of lung transplant candidates. *Families, Systems, and Health*, 19, 181-197.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Lambert B.L., Street R.L, Cegala, D.J., Smith, D.H., Kurtz, S., & Schofield, T. (1997). Provider-patient communication, patient-centered care and the mangle of practice. *Health Communication*, 9, 27-43.
- Lorber, J. (1997). *Gender and the social construction of illness*. Thousand Oaks, CA: Sage.
- McNeff, E. A. (1997). Issues for the partner of the person with a disability. In M. L. Sipski & C. J. Alexander (Eds.), *Sexual functioning in people with disability and chronic illness: A health professional's guide* (pp. 595-616). Gaithersburg, MD: Aspen Publishers, Inc.
- McPherson, K.M., Brander, P., Taylor, W.J., & McNaughton, H.K. (2004). Consequences of stroke, arthritis and chronic pain; Are there important Similarities? *Disability and Rehabilitation*, 26, 988-999.

- Meijer, R., Van Linbeek, J., Kriek, B. Ihnenfeldt, D., Vermeulen, M., & DeHaan, R. (2004). Prognostic social factors in the subacute phase after a stroke for the discharge destination from the hospital stroke-unit. A systematic review of the literature. *Disability and Rehabilitation*, 26, 191-197.
- Miles, A. (1991) *Women, health, and medicine*. Philadelphia, PA: Open University Press.
- Murray, C.D., & Harrison, B. (2004). The meaning and experience of being a stroke survivor: An interpretive phenomenological analysis. *Disability and Rehabilitation*, 26, 808-816.
- Newsome, J.A., & Schultz, R. (1998) Caregiving from the recipient's perspective: Negative reactions to being helped. *Health Psychology*, 17, 172-181.
- Pound, P., Gompertz, P., & Ebrahim, S. (1999). Social and practical strategies described by people living at home with stroke. *Health and Social Care in the Community*, 7, 120-128.
- Richey, J., & Brown, J. (2006). *Cancer, communication, and the social construction of self: Modeling the construction of self in survivorship*. Harper Press.
- Rohrbaugh, M. J., Cranford, J. A., Shoham, V., Nicklas, J. M., Sonnega, J. S., & Coyne, J. C. (2002). Couples coping with congestive heart failure: Role and gender differences in psychological distress. *Journal of Family Therapy*, 16, 3-13.
- Rolland, J. S. (1994). In sickness and in health: The impact of illness on couples' relationships. *Journal of Marital and Family Therapy*, 20, 327-347.

- Schwandt, T. A. (2001). *Dictionary of qualitative inquiry (2nd ed.)*. Thousand Oaks, CA: Sage.
- Shukla, P. (2001) *The social construction of health: A discursive approach*. Paper submitted to the Health communication Division of the 2001 annual Convention of the Western States Communication Association. Coeur d'Alene, Idaho. February 23-27, 2001.
- Silverman, D. (2001). *Interpreting qualitative data: Methods for analyzing talk, text, and interaction (2nd ed.)*. Thousand Oaks, Ca: Sage.
- Speziale, B. A. (1997). Couples, sexual intimacy, and multiple sclerosis. *Journal of Family Psychotherapy*, 8, 13-32.
- Teasell, R., Doherty, T., Speechley, M., Foley, N., & Bhogal, S.K. (2002). Evidence based review of stroke rehabilitation. London, Ontario: Ministry of Health and Long Term Care & Heart and Stroke Foundation of Ontario.
- Visser-Keizer, A.C., Jong, B., Deelman, B.G., Berg, I.J., & Gerritsen, M. J. J. (2002). Subjective change in emotive, cognition and behaviour after stroke: Factors affecting the perception of patients and partners. *Journal of Clinical and Experimental Neuropsychology*, 24, 1380-3395.
- Weinert, C., & Long, K. A. (1993). Support systems for the spouses of chronically ill persons in rural areas. *Family Community Health*, 16, 46-54.
- White, M.A., & Johnstone, A.S. (2000). Recovery from stroke: Does rehabilitation counseling have a role to play? *Disability and Rehabilitation*, 22, 140-143.

Appendix

Informed Consent Form

Understanding the Perspective of Stroke Survivors

Dear Research Participant:

You are being asked to take part in a study about the experiences of stroke survivors. This study is for my master's research project. I am a Communications graduate student at the University of Alaska Fairbanks. There are two goals in this study. First, I'd like to learn more about how stroke survivors experience everyday life since their stroke. I'd also like to learn more about how it has affected your personal, social and relational understandings. You are being asked to participate because you have survived a stroke and have expressed a willingness to talk about it.

I will read this form to you and you may ask any questions you have at any time. If you decide to be in the study, I will talk with you for about an hour about your experience after your stroke. I may ask you follow-up questions based on what you tell me. I will audiotape our interview, and transcribe the content of the tape. I will use the content of the recording as data for my thesis research.

Being in the study shouldn't present any risks, but you may feel sad or upset while talking about your experiences. If you don't like talking about your experiences since your stroke, you can decide not to participate. A possible benefit to being in this study is the chance to express your feelings and reflect on your life as a stroke survivor. It may also increase your understanding of how health and illness play a role in today's society.

Even if you decide to be in the study now, you may change your mind later. If you choose to withdraw, you can call me or my adviser at the email address or phone numbers below. You may choose to have your interview materials given back to you or tell me to erase the tapes and shred the transcripts. *Participating in this study is completely voluntary. You are free to change your mind about being in the study at any time.*

Your name and your responses will be kept private. The data derived from this study could be used in reports, presentations, and publications, but you will not be identified by name. The audiotape used in our interview and the transcript of it will be securely stored for five years in the UAF Communication Department. The only other person who will have access to these is my adviser, Dr. Robert Arundale. He is a professor with the Communication department and my Committee Chair. I am working on my thesis under his guidance.

If you have questions now, please feel free to ask. If you have questions later, you may contact me, Mary Gelinas, at 907-474-1876 or ftmfg@uaf.edu. You may also contact my adviser, Dr. Robert Arundale at 474-6799 or ffrba@uaf.edu. If you have questions or concerns about your rights as a research participant, please contact the Research Integrity Administrator at 474-7800 (1-866-876-7800 outside of Fairbanks) or fyirb@uaf.edu.

If you would be interested in my project results or in reading my thesis after it's published, please let me know and I will make a copy available to you.

Thank you for participating in this study. Please confirm at this time that you are willing to participate and understand the content of the Consent Form as I've read. You may ask any questions you may have about the study at any time. You have been given a copy of this form to keep.